The Narrated Lives of People
Affected by Acquired Brain Injury
Living in Rural Areas

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# Table of contents

**Volume 1**

- List of figures .......................................................... viii
- List of tables .............................................................. ix
- Acknowledgements ...................................................... x
- List of abbreviations ................................................... xi
- Abstract ........................................................................ xii

**ACT I – characters, situation and thread of the story**

**Chapter 1: Introduction** ................................................ 2
- 1.1 Introduction to the chapter ........................................ 2
- 1.2 Acquired brain injury ................................................ 2
  - 1.2.1 Definition ......................................................... 2
  - 1.2.2 Epidemiology of ABI in the UK ......................... 3
  - 1.2.3 Severity ........................................................ 4
  - 1.2.4 Epidemiology of ABI in the North-East of England .. 5
  - 1.2.5 Social factors .................................................. 6
- 1.3 Significant others in the lives of people with ABI .......... 7
- 1.4 Engagement in occupations in the western world ......... 9
- 1.5 The socio – cultural context of the study: The rural UK setting ... 11
- 1.6 The emphasis on current research to date .................. 12
- 1.7 Narrative ............................................................ 13
  - 1.7.1 Narrative research versus scientific research ......... 13
  - 1.7.2 Potential benefits of telling the narrative .............. 13
- 1.8 Chapter summary .................................................... 14

**Chapter 2: People as occupational beings** ....................... 16
- 2.1 Introduction to the chapter ...................................... 16
- 2.2 Occupation as a concept ......................................... 16
  - 2.2.1 Occupation as distinct from activity .................. 16
  - 2.2.2 The influence of context, culture and place on occupation .. 17
  - 2.2.3 Occupation and the experience of being with others ... 19
- 2.3 Occupations impacting on the individual ................... 19
  - 2.3.1 Doing, being, belonging and becoming though occupations .. 19
  - 2.3.2 Occupation and meaning .................................. 21
  - 2.3.3 Occupations and motivation to engage ................. 22
- 2.4 Habits and roles and forming the occupational identity .... 24
  - 2.4.1 Habits and roles .............................................. 24
  - 2.4.2 Occupational identity ....................................... 26
  - 2.4.3 Occupation and work ....................................... 27
- 2.5 A balance of occupations for health ......................... 31
  - 2.5.1 Occupational balance ...................................... 31
  - 2.5.2 Occupation and health ..................................... 32
- 2.6 Chapter summary ................................................... 33

**Chapter 3: Narrated lives** ............................................ 35
- 3.1 Introduction to the chapter ...................................... 35
- 3.2 The narrative mode of cognition ............................. 36
- 3.3 Meaning-making in the narrative ............................. 38
  - 3.3.1 Emplotment .................................................... 38
  - 3.3.2 Meaning-making and transaction ....................... 39
ACT II – Obstacles encountered

Chapter 4: Disruption of occupations and the narrative with ABI: the person with ABI and significant others affected by the brain injury

4.1 Introduction to the chapter
4.2 Occupational disruption for people with ABI
4.3 Occupational identity and ABI
4.4 Social integration issues following ABI
4.5 Work disruption for people with ABI
4.6 Occupational disruption for significant others in the lives of people with ABI
   4.6.1 Stress and strain in the care giving role
   4.6.2 Rewards in the role of giving care to people with ABI
   4.6.3 Occupational disruption in the role of giving care to people with ABI
4.7 Narrative disruption
   4.7.1 Narrative disruption for people with illness or acquired disability
   4.7.2 Narrative disruption and ABI
   4.7.3 Narrative disruption and the impact of identity with ABI
   4.7.4 Narrative disruption and the significant other
4.8 Research aims
4.9 Research purpose
4.10 Chapter summary

Chapter 5: Narrative as Methodology

5.1 Introduction to the chapter
5.2 Ontological and epistemological positions
5.3 Positionality
5.4 Theoretical perspectives
5.5 Narrative methodology
   5.5.1 Narratives within research
   5.5.2 Case study research
5.6 Quality of the research
5.7 Ethical considerations
5.8 Chapter summary

Chapter 6: Method

6.1 Introduction to the chapter
6.2 Participants and sampling
   6.2.1 Sample size
   6.2.2 Sampling method
   6.2.3 Recruitment
6.3 The interview
6.3.1 Interview structure ................................................................. 86
6.3.2 Piloting the interviews ............................................................ 88
6.4 Prompt tools ................................................................................. 89
  6.4.1 Life history grids ................................................................. 89
  6.4.2 Art ............................................................................................. 90
  6.4.3 Poetry ....................................................................................... 91
  6.4.4 Photography ........................................................................... 92
6.5 Assuring quality in the method ..................................................... 94
  6.5.1 Reflexivity ............................................................................... 94
  6.5.2 Credibility, transferability, dependability and confirmability ....... 95
6.6 Researching ethically ................................................................. 97
6.7 Methods of analysis ...................................................................... 99
  6.7.1 Analysis of narratives in general ............................................. 99
  6.7.2 Narrative analysis and analysis of narratives ......................... 101
    6.7.2.1 Narrative analysis ............................................................... 101
    6.7.2.2 Paradigmatic analysis of narrative data ......................... 102
  6.7.3 The steps in the process of analysis ....................................... 103
  6.7.4 Analysis of photographs ....................................................... 104
6.8 Chapter summary ......................................................................... 106

Act III – Resolution

Chapter 7: The stories analysed: Narrative aspects ........................ 107
  7.1 Introduction to the chapter ......................................................... 107
  7.2 The research participants and the handling of the data to write
    the stories ....................................................................................... 107
  7.3 Biographical disruption in the narratives ................................... 109
  7.4 Narrative analysis of the life stories: Two selected cases .............. 110
    7.4.1 Narrative analysis of a life story from an individual with an ABI:
      Bruce ............................................................................................ 110
      7.3.1.1 Bruce’s story .................................................................. 111
    7.4.2 Narrative analysis of a life story of an individual who has a
      significant other with an ABI: Doug ........................................... 116
      7.3.2.1 Doug’s story ................................................................. 116
  7.4 Chapter summary ....................................................................... 124

Chapter 8: The stories analysed: Narrative tone, typologies and analysis of
  narrative aspects ............................................................................. 126
  8.1 Introduction to the chapter ......................................................... 126
  8.2 Narrative tone and typologies in the overall narratives ............... 126
    8.2.1 Optimistic and pessimistic narrative tone in the narratives ...... 127
    8.2.2 Typologies of quest, chaos and restitution in the narratives ...... 130
    8.2.3 Literary genres of the narratives .......................................... 131
  8.3 Analysis of narrative ................................................................... 132
    8.3.1 Analysis of narrative of a person with an ABI: Christopher ...... 133
      8.3.1.1 Positional aspects of Christopher’s narrative interview ...... 133
      8.3.2.2 Analysis of Christopher’s interview .................................. 133
    8.3.2 Analysis of narrative of a person who has a significant other
      with an ABI: Rita ....................................................................... 145
      8.3.2.1 Positional aspects of Rita’s narrative ................................ 145
      8.3.2.2 Analysis of Rita’s narrative ............................................ 146
      8.3.2.3 Additional notes ............................................................ 154
  8.4 Chapter summary ....................................................................... 154
Chapter 9: The stories analysed: Occupational aspects

9.1 Introduction

9.2 Thematic analysis of narrative data

9.3 Barriers and enablers to engagement in occupations due to ABI

9.3.1 Symptoms of ABI and other health factors

9.3.1.1 Physical limitations

9.3.1.2 Behavioural and cognitive issues

9.3.2 Social capital, infrastructure and support

9.3.2.1 Social capital

9.3.2.2 The benefit system and finances

9.3.2.3 Specialist services for ABI

9.3.3 Stigma and identity issues

9.3.4 The emotional aspect

9.3.5 Rural living

9.3.6 The impact on roles

9.4 Strategies employed to cope with engagement in occupations due to ABI

9.4.1 Managing identity

9.4.2 Drawing on social capital

9.4.3 Positively moving forward in life

9.4.4 Practical coping techniques

9.4.5 Adopting particular behaviours

9.4.6 Engagement with spirituality

9.5 Occupational analysis of the whole narratives

9.5.1 The emerging pattern of a persistent theme in occupation

9.5.1.1 Case Selection 1: Rita: the special educational needs teacher and social care worker

9.5.1.2 Case Selection 2: Rachel: aspired to be a nurse

9.5.1.3 Case Selection 3: Hilary: pharmacist

9.5.1.4 Case Selection 4: Christopher: the PhD student in engineering

9.6 Chapter summary

Chapter 10: Discussion

10.1 Introduction to the chapter

10.2 The utility of the narratives

10.2.1 The utility of the twelve stories in storied form

10.2.1.1 The participant’s use of their own narrative

10.2.1.2 Use of narratives in health & social care settings

10.2.1.3 Use of the narratives for others in similar situations

10.3 Barriers and enablers to occupational engagement and coping strategies employed

10.3.1 Living with the symptoms of ABI and the consequences

10.3.1.1 Physical symptoms

10.3.1.2 Cognitive and other psychological issues

10.3.1.3 Symptoms impacting on engagement in occupations

10.3.2 The ABI experience enabling occupations

10.3.3 Managing identity

10.3.3.1 Social identity

10.3.3.2 Disability status, identity salience and guarding identity

10.3.4 Social capital, infrastructure and support

10.3.4.1 Social capital

10.3.4.2 Health services

10.3.5 Rural issues

10.4 An occupational persistence
10.4.1 Cultural capital, habitus and cognitive schema .......................... 201
10.4.2 Occupational capital and embodied occupational identity .......... 204
10.5 Occupational therapy interventions: utilisation of the embodied occupational identity .................................................. 206
10.6 Limitations ........................................................................ 209
10.7 Future research .................................................................. 212
10.8 Recommendations for future practice, policy and education ....... 213
10.9 Chapter summary .............................................................. 214

Chapter 11: Conclusion .............................................................. 216
11.1 Introduction to the chapter .................................................. 216
11.2 Narrative form .................................................................. 216
11.3 How engagement in occupations and roles is constructed in the narrative: revaluation of the embodied occupational identity .......... 219

References ............................................................................. 221

Volume 2

Appendix A – Information sheet (flyer)........................................... 256
Appendix B – Information sheet (Word document) ......................... 258
Appendix C – Instructions for the final interview ......................... 260
Appendix D – Comments from a participant on returning their emplotted story .......... 262
Appendix E – Length of Interviews .............................................. 264
Appendix F – Consent sheet......................................................... 265
Appendix G – Debrief sheet ....................................................... 266
Appendix H – Ethical approval letter ........................................... 267
Appendix I – Coding frame for analysis ....................................... 268
Appendix J – Model for photographic analysis ............................... 270
Appendix K – Examples of Narrative Analysis Tables – Participant 3, Angie ............................. 272
  - 1. Life story ................................................................. 273
  - 2. Events question ....................................................... 284
  - 3. Illness experience .................................................. 292
  - 4. Roles ................................................................. 299
  - 5. Activities ............................................................ 305
  - 6. Rural living .......................................................... 312
Appendix L – Example of participant photographs – Participant 3, Angie ............................. 313
Appendix M – Example of photographic analysis – Participant 3, Angie ............................. 315
Appendix N – Example of coding frame for analysis – Participant 3, Angie ............................. 317
Appendix O – Example of narrative analysis – Participant 3, Angie ............................. 326
Appendix P – Example of analysis of narrative – Participant 3, Angie ............................. 334
Appendix Q – Verification of Angie’s story .................................. 343
Appendix R – The Remaining Narrative Analyses (not contained in the main thesis or example offered above) .......................... 344
  - Participant 1 – Rachel’s story ....................................... 345
  - Participant 2 – Sam’s story ......................................... 353
  - Participant 5 – Susan’s story ...................................... 361
  - Participant 6 – Hilary’s story ...................................... 369
  - Participant 7 – Helen’s story ....................................... 381
  - Participant 8 – Christopher’s story ............................. 389
  - Participant 10 – Elizabeth’s story ............................... 397
  - Participant 11 – Diana’s story .................................... 403
  - Participant 12 – Rita’s story ....................................... 411
Appendix S – The Remaining Analysis of Narratives (not contained in
the main thesis or example offered above).................................419
- Participant 1 – Rachel – A care giver’s story.........................420
- Participant 2 – Sam – A man with a brain injury who is
terminal ill..............................................................................428
- Participant 4 – Bruce – A retired policemen..........................437
- Participant 5 – Susan – A nurse’s story.........................444
- Participant 6 – Hilary – A chaos narrative..........................456
- Participant 7 – Helen – A wife and carer’s story...........465
- Participant 9 – Doug – A husband’s story.....................474
- Participant 10 – Elizabeth – A wife’s story..........................483
- Participant 11 – Diana – A mother and carer’s story.........490

Appendix T – Thematic analysis table – Barriers and enablers to
occupational engagement..........................................................498

Appendix U – Thematic analysis table – Strategies employed to cope
with engagement in occupations due to ABI..........................503

Appendix V – Occupational aspects of the narratives....................506
List of figures

Figure 1 - The relationship between occupation, narrative and identity
List of tables

Table 1 – Participant demographics
Table 2 - Narrative tone and typologies in overall narratives
Table 3 - Work occupations of participants
Table 4 – Length of interviews (Volume 2)
Table 5 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 1. Life story
Table 6 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 2. Events question
Table 7 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 3. Illness experience
Table 8 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 4. Roles
Table 9 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 5. Activities
Table 10 - Examples of Narrative Analysis Tables – Participant 3, Angie
  - 6. Rural living
Table 11 - Example of photographic analysis – Participant 3, Angie
Table 12 - Example of coding frame for analysis – Participant 3, Angie
Table 13 - Thematic analysis table – Barriers and enablers to occupational engagement
Table 14 - Thematic analysis table – Strategies employed to cope with engagement in occupations due to ABI
Table 15 - Occupational aspects of the narratives
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This thesis is dedicated to my family: Ian, Jenny, Mark, Mum, Dad and Sarah, who both support and inspire me in the course of my own life narrative.
**List of Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABI</td>
<td>acquired brain injury</td>
</tr>
<tr>
<td>BNIM</td>
<td>Biographic-narrative-interpretive-method</td>
</tr>
<tr>
<td>BSRM &amp; RCP</td>
<td>British Society of Rehabilitation Medicine and Royal College of Physicians</td>
</tr>
<tr>
<td>COT</td>
<td>College of Occupational Therapists</td>
</tr>
<tr>
<td>COTSSNP</td>
<td>College of Occupational Therapists Specialist Section in Neurological Practice</td>
</tr>
<tr>
<td>HCPC</td>
<td>Health &amp; Care Professions Council</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>MOHO</td>
<td>Model of Human Occupation</td>
</tr>
<tr>
<td>NASA</td>
<td>National Aeronautics and Space Administration</td>
</tr>
<tr>
<td>NHS</td>
<td>National health service</td>
</tr>
<tr>
<td>OCD</td>
<td>Obsessive compulsive disorder</td>
</tr>
<tr>
<td>RCT</td>
<td>randomised controlled trial</td>
</tr>
<tr>
<td>SO</td>
<td>significant other</td>
</tr>
<tr>
<td>SQUIN</td>
<td>Single Question aimed at Inducing Narrative</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organisation</td>
</tr>
</tbody>
</table>
Abstract

Disruption to the life narrative is a common long-term experience following acquired brain injury. It can lead to barriers in being able to fulfil roles and engage in daily activities and occupations. Disruption occurs not only for the person who sustains the brain injury, but is also an experience for significant others in their lives. This narrative study gathered participants’ personal ‘sense making’ of life events following such disruption. Extended narrative interviews were combined with a photo-elicitation technique for six people with acquired brain injury and six people who had a significant other in their life with an acquired brain injury, all living in a rural area. It involved discussion around the patterning of their daily activities and roles both pre and post injury.

Narrative analysis led to individual case studies of barriers and opportunities to lives impacted by brain injury. Issues were highly individualised and whilst the rural context presented an advantageous place to live for some due to tranquillity, it was less advantageous for others. However, synthesis of findings across cases considered the narrative form produced by the twelve accounts. This revealed that individuals drew on attributes of previous roles and careers to construct meaning and manage their lives, even when they could no longer engage with past roles and careers.

Approaches to self-management post injury appeared to follow a pattern of drawing on internal schema underpinned by values, skills and meaning of previous roles and careers. This constitutes a form of capital built up from life pre-injury that is being utilised to achieve health and wellbeing, which I have called ‘embodied occupational capital’. An opportunity to work with individuals whose lives are affected by acquired brain injury has been offered, by way of focusing on this ‘embodied occupational capital’ to empower them to make positive change.
Volume 1
Act I Characters and complications

Chapter 1 Introduction

1.1 Introduction to the chapter

“It’s a mammoth thing. Brain injury is a mammoth thing I’ve found. Erm... I don’t
know where to begin because I had a life erm... this is like my second life. I had a life
before brain injury and a life after...”

This is how one research participant, Christopher, began his story about living with
an acquired brain injury (ABI). He acquired the brain damage from removal of a
brain tumour, followed by a cerebral vascular accident (or stroke). This quote from
Christopher and his narration of daily life as being different following ABI, links to the
underpinning principles of this research. This research concerns his engagement in
daily occupations and the type of location in which he lives. Furthermore, such a
situation may touch the lives of others, who have not experienced an ABI
themselves, but by virtue of being a significant other in the life of someone else with
an ABI might be affected. This research considers stories of lives that have been
affected by ABI and any subsequent biographical disruption.

1.2 Acquired brain injury

1.2.1 Definition

Any injury to the brain that occurs after birth can be defined as an acquired brain
injury, (acquired meaning ‘developed after birth through the influence of the
environment’ (New Shorter Oxford English Dictionary, 1994)). ABI causes are both
numerous and varied. They are categorised as traumatic brain injury or non-
traumatic brain injury, depending on associated aetiology. Traumatic brain injury is
caused by a physical force to the head and results in either an open or closed insult
(UKABIF, 2013). It can also be caused by post-surgical damage, for example
following removal of a tumour (British Society for Rehabilitation Medicine and Royal
College of Physicians [BSRM & RCP], 2003). But how does this differ from non-
traumatic brain injury? Non-traumatic brain injury causes are many and varied, such
as a cerebral vascular accident (commonly known as stroke), bodily ingestion of
toxins, infection, tumour and metabolic disturbance (UKABIF, 2013; Headway 2015). Predominantly most presentations of ABI in the UK come from trauma and stroke, in almost similar measures (BSRM & RCP, 2003; Tennant, 2005; Headway, 2015).

1.2.2 Epidemiology of ABI in the UK

ABI is relatively common within the UK population. However, obtaining accurate data about the numbers of ABIs in the UK is less than straightforward, due to the varying aetiologies and how incidences are recorded by the health services. Hospital admission statistics can be used as a guide but do not lead to an indication of how many people will have long term effects of injury (BSRM & RCP, 2003; UKABIF, 2013; Headway, 2015). Errors and bias are always difficult to avoid in generating epidemiological data, as it is being generated from the complexity and heterogeneity of human life (Bhopal, 2008). This is certainly the case in ABI, where the causes are both numerous and varied, plus the degree of effect of the injury leads to complexities in classification (BSRM & RCP, 2003). That said, statistics give no indication of any resulting disability experienced by the individual, which can be diverse and ranges from very mild to very severe.

Research suggests that the occurrence of ABI is changing. The trend in the number of people presenting at accident and emergency departments in England for traumatic brain injury is upwards, with the brain injury charity, Headway, having seen much more demand for its services in recent years (Headway, 2015). In 2013 this was recorded as 285.5 per 100 000 (Hawe, Baillie & Schaffer, 2013). Only a proportion would warrant being admitted to hospital, but overall the picture has been one of rising numbers. From the perspective of gender, men are approximately twice as likely to sustain a traumatic brain injury than women, (Health and Social Care Information Centre, 2012; Richardson, 1990), though the updated Headway study suggests the difference is far less (Headway, 2015). Furthermore a cross-representation of the community is not seen in people with traumatic brain injuries: young, extrovert males are commonly represented (Rose, 1999). This is due to the risk-taking type of activities they are more likely to engage in, sometimes with dire consequences. A large number of recorded hospital admissions in this category are from road traffic accidents (Hawe, Baillie & Schaffer, 2013). Substance abuse within this younger age group, or any other, may play a part. People with mental health problems, at any age, may also be overly represented (Rose, 1999), though it is not
clear whether this is due to risk-taking activities they undertake due to mental health issues, or the actual experience of living with a brain injury leading to mental health issues such as depression. The consequence is that there are a large number of people of working age living with resulting disability from a traumatic brain injury (Tennant, 2005). The number of people living with the disabling effects of a traumatic brain injury in England is estimated at approximately 910 000 (UKABIF, 2013) and ongoing support is required for these people (Headway, 2015).

The incidence for cerebral vascular accident, or stroke, has a different variation to that for traumatic brain injury. The estimated occurrence of strokes in the UK is about 150 000 per year (Stroke Association, 2013). However, up to 75% of these, affect people over the age of 65, (Different Strokes, 2012). This still leaves a considerable number of people of working age with the side effects of stroke in the UK and possible resulting disability (over 37 000 per year).

The average age of people experiencing a stroke for the first time is very different to the typical young males experiencing a traumatic brain injury. For women it is about 77 years and for men 71 years, (Lee, Schafe & Cowie, 2011). Only about 25% of first strokes occur in the under-65 age group, with approximately 300 000 people living with a moderate to severe disability as a result of stroke (NAO, 2010). Incidence rates for the less common causes of ABI are even harder to gauge accurately than for traumatic brain injury and stroke.

Not forgetting some of the less common forms of ABI, incidence data for encephalitis is in excess of 700 cases per year (Granerod & Davies, 2012). Where data has been recorded for the incidence of brain tumour, it gives no indication as to whether or not there is any residual brain injury due to surgical removal of the tumour.

1.2.3 Severity

Having considered the occurrence of ABI in the UK attention turns to severity of the actual injury that individuals are living with. Information on the severity of the ABI and resulting disability is not available, but most people admitted to hospital with such a presentation survive (Headway, 2015). The severity of traumatic brain injury at the time of injury is often described in terms of the duration and extent of the individual’s impaired consciousness, evaluated by the Glasgow Coma Scale’s
measures of motor, verbal and eye-opening responses (Teasdale & Jennett, 1974). The use of the same scale does not apply to non-traumatic forms of ABI, thus making classification difficult for this other category of ABI. In summary, if we combine the number of people living with the moderate to severe disabling effects of a traumatic brain injury and stroke in the UK, a significant amount will be of working age, yet living with significant disabilities.

Although living with ABI does not impact on life expectancy, potential residual symptoms may be apparent, with variation in how people are affected. Disability issues for individuals with ABI are often varied and complex, requiring differing levels of assistance and support (BSRM & RCP, 2003). The younger person typically presents differently to the older person with a stroke, in that the pattern of impairment is more varied. The younger brain can display more neuroplasticity, thus being more receptive to the long periods of rehabilitation (BSRM & RCP, 2003). Impairments tend to be classified as physical, cognitive, communicative and behavioural/emotional (BSRM & RCP, 2003). One individual may display paralysis and abnormal muscle tone, another memory problems or mood change, whilst yet another may display a combination of both with additional deficits: the picture is incredibly varied. A proportion of individuals with a mild head injury will have resulting cognitive deficits which may not be obvious at first, but go on to impact on social, family and work relationships (BSRM & RCP, 2003).

1.2.4 Epidemiology of ABI in the North-East of England

Attention now turns to any potential regional variations in epidemiology. Tennant’s 2005 study considered geographical location of people presenting in hospital departments with a traumatic brain injury. High incidence was associated with Midlands and Northern urban areas, particularly where there was high youth unemployment and low use of public transport to work (Tennant, 2005). It would appear that an area with a high deprivation index, such as an inner London borough, could have the high incidence rate offset by virtue of having a strong transport infrastructure. Good public transport links thus reduce the incidence of brain injuries. The highest incidence was found on Teesside and Merseyside (Tennant, 2005). As with traumatic brain injury, geographical differences are linked to incidence of stroke. Areas with higher levels of deprivation can experience a three-fold increase in incidence, compared with areas of low deprivation. North of England and Scotland have particularly high incidence rates (Scarborough et al.,
The incidence is likely to be lower where the average age of the population is younger also, for example in London (Scarborough et al., 2009).

Thus the north-east of England is an area for high incidence and prevalence for both major categories of ABI. Some rural areas of north-east England present particularly high statistics for hospital admissions for traumatic brain injury: 639 per 100 000 of the population for NHS Northumberland; 690 per 100 000 for NHS Durham Dales, Darlington, Easington and Sedgefield, compared with only 544 per 100 000 for the UK nationally (Headway 2015). In terms of traumatic brain injury the prevalence is recorded as 30 668, which is people living with the effects of a traumatic brain injury, across the whole of the region (NEPHO, 2009). No accurate data is available in terms of numbers of people living with varying severity of ABI in the region and the extent of their resultant disabilities.

1.2.5 Social factors

A typical bio-medical approach to ABI rehabilitation would be to focus on individual change, remediating functional deficit. Yet a person in the situation of having health and wellbeing needs is living in a broader social context, which must be acknowledged and taken into account (Murray, 2014). The social context will encompass such as the socio-economic environment, the culture and relationships of the person with ABI. Within culture, dominant social representations may conventionalise individuals from social groups (Moscovici, 2000), such as people with disabilities generally being seen as deficient, despite the aforementioned variety and complexity of how ABI presents. How such groups become socially represented becomes the environment in which they live (Moscovici, 2000).

Social cognitive skills are commonly affected by ABI, leading to being less able to manage the interpersonal cues that are processed for social behaviour. This may involve being less able to perceive or relate to the emotions of others, effect the interpretation of other’s intentions or display empathy (McDonald, 2013). This can present the individual with ABI with substantial challenges in social functioning, both within and outside of family and friendship groups (Douglas, 2013). The combination of this multiplicity of social factors can make the construction of self difficult to renegotiate post-injury (Douglas, 2013).
1.3 Significant others in the lives of people with ABI

Thus, the effect on people’s lives is far more wide-ranging than just on the individual with the ABI. Individuals mostly live within families and if they acquire a brain injury they typically require a significant other person in their family or social circle to be involved as a carer. Those with more severe brain injury will have more reliance on carers, paid or unpaid, full or part-time. Even if a significant other person in the family does not identify themself as a carer, life will be affected by the after effects of the ABI. The effect of caring on the lives of those who undertake this role has been researched across many illnesses and disabilities, revealing both negative and positive consequences of caring, though the majority of reports emphasise the negative impact. Research by Carers UK suggests that more than half of carers feel stressed about being able to care well and let their own health problems go untreated. Three in four carers considered their role as not being valued in the community or understood (Carers UK, 2016).

Being a carer can have an impact on significant others within the family environment. The giver of care can often feel that they are uncertain if they are doing enough for the care recipient (Hasselkus & Murray, 2007), or feel uncertain about the future (Heward, Molineux & Gough, 2013; Martin, 2012). Decision-making about balancing and promoting the independence of the individual can lead to difficulties (Martin, 2012). Daily occupations of the carer can be constrained due to undertaking the role. The chronic illness of the care recipient forces major changes on daily routines of the carer (Hasselkus & Murray, 2007; Heward, Molineux & Gough, 2013; Martin 2012).

Marital dissatisfaction where one partner has an ABI is common (Charles, Butera-Prinzi & Perlesz, 2007; Degeneffe, 2001; Eriksson, Tham & Fugl-Meyer, 2005; Braine, 2011). Verbal and physical abuse is associated with frontal lobe damage and may be directed towards partners and children (Charles, Butera-Prinzi & Perlesz, 2007; Hanks, Rapport & Vangel, 2007) Increased responsibilities and taking on multiple roles can result in family relationship changes (Braine, 2011; Carozzi et al., 2015). Relationships can be affected by no longer being able to maintain an intimate relationship: the partner with the ABI may be withdrawn, detached or hostile, leaving the remaining partner feeling rejected (Ben Azri, Solomon & Dekel, 2000).
Stress is common due to caring for someone with an ABI (Moules & Chandler, 1999; Perlesz, Kinsella & Crowe, 2000; Wood, Liossi & Wood, 2005). Caring has been found to have a negative impact on caregivers’ mental health by elevating levels of depression (Blake, 2008; Berg et al., 2005; Savage & Bailey, 2004). The quality of life of carers has also been reported as reduced (Blake, 2008; Jackson et al., 2009; Cummins, 2001). Carer wellbeing can be associated with the wellbeing of the person with the ABI (Jumisko, Lexell & Soderberg, 2007a).

The negative impact of caring for someone with an ABI differs from caring for people with alternative medical conditions. It may be that the negative mental health aspects are poorer for carers of people with some conditions than others, e.g. worse for people caring for someone with ABI than someone caring for someone with dementia, especially if aggression is experienced by the care recipient (Jackson et al., 2009). If the care recipient is intellectually intact and has less behavioural problems the negative mental health aspects of caring are experienced less (Savage & Bailey, 2004; Tam, McKay, Sloan & Ponsford, 2015). The degree of brain injury impairment is an independent predictor of carer burden one-year post injury (Bayen et al., 2013), with executive functioning impairment in particular (Sander, Maestas, Clark & Havins, 2013). Behavioural issues can have a direct negative effect on the functioning of the family (Anderson et al., 2013; Ponsford & Schonberger, 2010). Entire families may find their lives transformed (Headway, 2013). Relationship breakdown is common between partners, primarily due to unpredictable patterns of behaviour (Wood, Liossi & Wood, 2005).

Caring tends to be viewed in pathological terms (Grant, Ramcharan, McGrath, Nolan & Keady, 1998). Indeed, there is a tendency for research to focus on the negative aspects of coping and more could be done in research to focus on positive outcomes to redress the balance (Folkman & Moskowitz, 2000). Indeed, the experience of caregiving itself can be satisfying. Pervasive benefits of caring for someone can come from appreciation for undertaking the role, acquisition of new skills and providing a sense of purpose in life (Grant, Ramcharan, McGrath, Nolan & Keady, 1998). This may well be down to the demands of caregiving engendering a strong sense of one’s ability to cope with difficult situations (Wells, Dywan & Duams, 2005). Lower stress levels are associated with being able to cope with difficult behaviours (Riley, 2006). Positive aspects of coping can co-occur with distress, with an individual being happy for some of the week in which stressful events occur (Folkman & Moskowitz, 2000). A push-pull tension in everyday life can result due to
this co-existence of stresses and rewards (Grant et al., 1998). Positive and negative experiences of involvement with health professionals may add to this (Hasselkus & Murray, 2007).

Much will depend on the intrapersonal qualities of the carer and a positive orientation of the carer can be an important predictor of rewards being experienced (Blais & Boisvert, 2007; Grant et al., 1998). Carers commonly reappraise the situation of caregiving in a meaningful way and this can mediate against stresses if considered in terms of demonstrating love and preserving the dignity of the care recipient (de Arroyabe et al., 2013; Folkman & Moskowitz, 2000; Hasselkus & Murray, 2007). Being a caregiver for a relative within the family may increase ties and the family as a whole may benefit (Grant et al., 1998). Social networks can be expanded as a result of engagement with a new community of people also engaged in caring for people with disabilities (Grant et al., 1998; Hasselkus & Murray, 2007; Heward, Molineux & Gough, 2013). Satisfaction may be experienced from moments of wellbeing with the care recipient (Hasslekus & Murray, 2007). For some an investigative vocation around the diagnosis may result (Heward, Molineux & Gough, 2013).

1.4 Engagement in occupations in the western world

Having introduced the occurrences of ABI and the broad impact on lives, the focus now turns to how ABI impacts on participation in daily occupations. Reduced opportunities for engagement in occupations may be a consequence for someone with an ABI or their significant other (SO). Engagement in occupation is a fundamental part of life. It allows for social interaction and can contribute to spiritual wellbeing. It exercises the mind and body for the promotion of health (Wilcock, 2001). The World Health Organisation (WHO) recognised and continues to promote, a bio-psychosocial approach to health (WHO, 2001). Through its development of the International Classification of Functioning, Disability and Health (ICF) there has been an attempt to recognise experiences of disability as a mainstream universal human experience, rather than a medical model of healthcare that places impairment and the individual's health deficits at the centre (WHO, 2001). Linked to the human experience of disability, the ICF defines participation as ‘involvement in a life situation’. It advocates the idea that societal engagement is influenced by not only one’s personal health characteristics, but societal, physical and attitudinal
factors in the environment. Participation as defined by the WHO, draws parallels with occupational engagement, a focus for occupational therapists and also the research discipline of occupational science, which studies humans as occupational beings (Yerxa et al., 1989). One of the seminal thinkers in occupational therapy, Mary Reilly, put forward a hypothesis over fifty years ago; “That man, through the use of his hands as energized by mind and will, can influence the state of his own health.” (Reilly, 1962, p88.)

Reilly is referring to the use of occupation as a tool for health and wellbeing and suggesting that good health is intrinsically linked to being able to engage in fulfilling occupations. In this context occupations are considered more than a chosen career, but the actual performance of even small activities that people need or want to do as part of their daily life and daily tasks (Canadian Association of Occupational Therapists, 2011; Wilcock & Hocking, 2015). The occupations people are engaged in are often determined by the roles they undertake e.g. family member, worker, friend (Kielhofner, 2008). A personal patterning of roles develops for each individual as they move into adulthood, with this patterning developing into an integrated adult identity. This can include sexual, racial, national, class and work identity (Rayner, 1995). Identity can similarly determine occupational choices (Abrahams, 2008). This dynamic interaction of occupation, identity and choice is influenced by the societal, physical and attitudinal factors in the environment as proposed by the WHO above. Adults who have lived with disabilities may have been unable to make personal choices and occupational choices and maximise personal freedom, due to the societal, physical and attitudinal barriers presented by the environment. Personal choice and personal freedom are two highly valued aspects of western culture (Watson & Fourie, 2004).

Western culture also has a belief that wellbeing is linked to good income, sound financial status and employment (Wilcock & Hocking, 2015), sometimes initially unattainable for people with disabilities. This, for some has to be later forsaken due to poor health and lack of environmental adaptation. Wilcock, in her discussion of occupational evolution and industry, emphasises Marx’s recognition that work can actually be harmful in some circumstances, by stifling physical and intellectual potential along with unique talents: we should engage in occupations to promote fulfillment and well-being and often these occupations are outside of those that provide subsistence. This idea was further developed by some Victorian creative artists: the creation of wealth for its own sake over the quality of life society enjoys
was criticised (Wilcock & Hocking, 2015). It is with this premise in mind, that the function of occupation goes beyond the generation of wealth or individual breadwinning and includes daily maintenance activities and hobbies: creative, sporting, social, educational or other time filling.

1.5 The socio-cultural context of the study – the rural UK setting

Earlier the regional variation in occurrence of ABI was introduced. What was not discussed was whether the type of geographical location has an impact on daily living for people with ABI or significant others. There may indeed be particular issues for people with ABI and their families living in rural communities. A rural definition can be ambiguous and is non-standardised, meaning different things to different people, (for example an area of low density population and agricultural landscapes versus a small town). Rural is a culture-specific term in that a city dweller in urban England may define differently to a person living on a farmstead in Australia (Woods, 2005). Rural populations can vary from a small group of residents to a number of thousands. The Local Authority Rural-Urban Classification defines populations over 10,000 as urban, versus those with less than 10,000 as rural, but the rural aspect will be confounded by the proximity to urban areas (Department for the Environment, Fisheries and Rural Affairs, 2011). It could be assumed that as similar social and economic processes operate across all areas in the UK today, that with increasing transport and communication links the differentiation between urban and rural is irrelevant. However, Woods (2005), argues that many people still consider themselves to live in a rural area or follow a rural way of life and for them the issue of a locality is less significant than the perception of how people perceive themselves to have a rural identity. Woods (2005) explains this by taking a social constructionist approach to defining rural, in which the signs, symbols and images are considered that people associate with the term rural, generated by, for example, literature, the media and experience and thus can mean different things to different people (Woods, 2005). The people who consider themselves to be rural may associate themselves with these signs and symbols, despite living in a more populated area than following official definitions (Woods, 2005).

The idea of living in a rural community can evoke a positive image of the rural idyll with good health, an escape from modernity and harmonious social relations (Little & Austin, 1996). This links in with a rural identity formation and may also relate to
aspects of social exclusion and marginalisation. A neglected area of research is that of embodiment and rural geography, such as a consideration of the body within rural social spaces (Little & Leyshon, 2003). Particular issues of embodiment may belong to those who find themselves to be different in such communities, such as having the stigma of a disability or living with someone with the stigma of disability, (indeed bringing its own stigma). Access to health and rehabilitation services poses challenges to people living in rural areas, with services often being inaccessible, confounded by under-resourced community transport services (Health Development Agency, 2004). Similarly, people’s access to services may be poor in a larger town where there are poor transport links to major conurbations with specialist centres to cater for such as ABI.

**1.6 The emphasis on previous research to date**

Much of the previous research on lives affected post-ABI has been approached from the perspective of deficits in function and cognition, with a focus on remediation through statistically measurable goal setting. This is typically in the domains of physical, cognitive, communication and behavioural / emotional impairments (BSRM & RCP, 2003). For significant others, the focus has been on burden and the negative consequences of caring. Entering into research within the realm of sophisticated measurable techniques and statistics ensures that the research is aligned to the dominant scientific discourse (Murray, 2014). The duality of mind and body in this bio-medical discourse has at times been expanded to ‘biopsychosocial’, to include the ‘social’ (though restricted to social relations). Yet human thought and action within social contexts are complex by nature and have been avoided for analysis and explanation by dominant biopsychosocial approaches to research (Murray, 2014).

This results in gaps in research concerning people affected by ABI as occupational beings and the dynamic interaction of occupation and identity, influenced by such as societal and attitudinal factors. Little, if any research exists to date on the experience of living in the socio-cultural context of the UK rural setting for people affected by ABI (either those who sustain the ABI or those significant others who are family members), which may be quite different from the urban centres they travel to for healthcare services.
1.7 Narrative

1.7.1 Narrative research versus scientific research

The rapid advance of biomedicine in post-industrialised societies, such as the UK, may explain healthcare / health and illness research being dominated by medical science, with society’s health discourse being duly influenced (Wilcock & Hocking, 2015). Medical diagnosis and subsequent treatment remain objectively focused and are essential (Hurwitz, Greenhalgh & Skultans, 2004). But it is argued above that this fails to give a coherent picture of life with ABI, ignoring the social context. Furthermore, the disease focus of biomedicine serves to neglect the illness perspective and patient experience (Riessman, 2004) and ignores the inter-relationship between occupation, health and illness (Wilcock & Hocking, 2015). Adapting to chronic illness and the interruption of people’s lives through illness is indeed subjective rather than objective due to wide variations in individual circumstances. In light of this, narrative has challenged medicine to humanise clinical practice and see the patient as an individual person living in a complex social world (Mattingly, 2004).

1.7.2 Potential benefits of telling the narrative

So adopting a narrative approach may be justified from a research perspective, being critical of past bio-medical approaches. Additionally it may have benefits for the person as the subject of the research. Frank (1995) identifies the omission in medical practice of, “helping patients learn to think differently about their post-illness worlds and construct new relationships to those worlds” (p6), which can be achieved through narrative. A further potential for the narrative goes beyond influencing practice, to that of raising public awareness of illness and disability issues, as well being as a driver for policy change in health in social care (Mattingly, 2004).

A typical medical / patient interaction focuses on the current situation and often de-legitimises a continuity of past self brought forward to current self for people who have undergone life changing events (Mattingly, 1998). The person with the ABI may strongly resist this view of the new identity declared by the health professional and require an acknowledgement of strands of the former self brought forward in order for self-realignment and connecting with the past is still hugely important to
them (Gelech & Desjardins, 2010). This could be a key factor when moving forward in rehabilitation and easily missed by a bio-medical approach. Moving to a more empowering model of rehabilitation, the client may move to a more empowered and proactive state (Cloute, Mitchell & Yates, 2008).

There is further evidence that the process of constructing narratives is a useful tool in reconstructing the self and helping re-establish self-identity following ABI (Nochi, 1998; Heller, Levin, Mukherjee & Rees, 2006; Frank, 2010). Letting an individual tell their story of the past, from the perspective of the current situation, allows characters to emerge and play roles that gain new insights into their life. It helps to form new characters and roles to play in the present and how they potentially see themselves in the future. This helps the formation of a new sense of identity (Biderman, Daniels-Zide, Reyes & Marks, 2006). This may apply to significant others as they too have undergone biographical disruption following the ABI of a spouse or family member. Personal narration of experience allows individuals to express identity claims and conceive identity (Patterson, 2012). The narrative is subjectively constructed and in so doing draws on the individual’s imagination and allows for ‘the other’ to be conceptualised (Andrews, 2014).

Considering narrative as a personal story form throughout history, has there been any suggestion as to a pattern in the way in which it is expressed? Aristotle first proposed the basic linear narrative or story structure in Ancient Greece, in his book, Poetics (Barnes, 2000). The plot develops in three parts or acts, the beginning, middle and end (Aristotle/Kenny, 2013). The same principles of the three-act structure still typically apply to the telling of stories today (Field, 2005), suggested as fundamental to any narrative (Brutsch, 2015). The beginning sets up a dramatic presence, with characters and complications; the middle presents discoveries, obstacles and conflict to be overcome for the characters; the end brings resolution and questions answered (Thomson, 2003; Field, 2005, Brutsch, 2015).

1.8 Chapter summary

This research is underpinned by the elements discussed in this chapter, of ABI; its high prevalence within the north-east of England and rural areas; social factors; significant others; the impact on occupations and identity; and the telling of the personal narrative, typically in a three-act structure. It invited people whose life
stories had been disrupted by ABI to relay their narrative accounts. Participants were either (a) an individual who had acquired a brain injury (ABI), or, (b) an individual whose life had been disrupted by a significant other in their life acquiring a brain injury (SO). Both groups of people had experienced a significant disruption to their life story or narrative and lived in a rural location in the UK. Identified gaps in previous bio-medical and biopsychosocial research approaches justify an alternative research approach being required, that can encompass the social context and expose the issues presented to people affected by ABI as occupational beings. In acknowledgement of the research approach being taken forward as narrative, this thesis is presented similarly as a three-act structure. Act I comprises Chapters 1-3, where the characters, situation and thread of the story are introduced; Act II comprises Chapters 4-6, where there is development of the plot and; Act III is the resolution to this particular story and comprises of Chapters 7-11.
Chapter 2   People as occupational beings

2.1 Introduction to the chapter

“Normally you introduce, you introduce yourself by what you do, don’t you and I don’t do anything. I tend to introduce myself and tell them why I’m not working. In case, not in vast detail I would just say that I’ve had a brain injury and that’s why I’m not working.”

This quote by one participant, Hilary, reflects the impact of being unable to engage in one of her previous occupations, namely work, following an ABI. Her injury was acquired as a result of a subarachnoid haemorrhage in her mid-forties.

All human beings engage in occupations. From an anthropological perspective, the main difference between people from different cultures is the way in which they do things (Wilcock & Hocking, 2015). But what is doing and in what way do occupations differ from activities? What is the influence of the social context, habits, meanings, roles and identity in our understanding of these differences? And in what way are these factors connected to achieving a broad repertoire and balance of so called occupations and how does this impact on an individual’s health? In this chapter, in order to develop the thread of the story in this thesis, the various theoretical models will be discussed in line with the perspective of the author, who, as an occupational therapist, focuses on occupation as significant to the lives of individuals and places occupation as being central to the concepts of doing, being, becoming and belonging (Wilcock & Hocking 2015).

2.2 Occupation as a concept

2.2.1 Occupation as distinct from activity

With occupation being core to its practice, the profession of occupational therapy has most likely sought more definitions of occupation than any other. Through the development of the associated academic discipline of occupational science scholars have sought to establish a clear definition of occupation and distinguish it from the term activity (Christiansen, 1994; Christiansen, 1999; Pierce, 2001; Hasselkus, 2006; Kuo, 2011). An activity is considered to be a series of actions that are defined within a culture’s language (Pierce, 2001), such as the idea of driving or gardening, which were some of the activities relevant in this research. The activities are symbolic within the culture and even if not personally experienced, there will be a general understanding of what the activity involves due to them holding symbolic
meaning within the cultural context. Being able to assign symbolic meaning is considered to be a distinguishing feature of humans (Hocking, 2000). For example the activity may hold a gender-orientated meaning within a society, which may have been culturally defined, such as sewing as a female activity. Status may be assigned to other activities, such as driving an expensive car or being a member of a profession, such as a doctor or lawyer (high status), or collecting rubbish (low status). These considerations are significant, often unconsciously, when individuals consider their engagement in such activities.

It could be argued that there is a distinction between the term activity and the term occupation in academic terms, (whether or not this carries distinction in everyday life). Theoretically, occupation adds an additional layer to the idea of an activity, in that it is the experience an individual has whilst taking part in the culturally defined idea of that activity. This is a subjective, personally constructed experience, whether carried out alone or with others. Only that individual can precisely interpret what meaning the occupation has (Pierce, 2001). The internal or emic perspective of the individual experience will differ from the external or etic perspective of the observer of the occupation and may be influenced by such as the value someone places on it (Christianson, 1994). This relates to the idea of personhood, in that occupations are key to being a particular person, in light of this individual subjective experience (Christiansen, 1999). It could be argued that this proposed distinction between activity and occupation is superfluous and that the popular or lay sector of society does not distinguish between the two, suggesting a theoretical distinction only. However, it is useful to occupational therapy practitioners to appreciate the subjective experience of engaging in occupations for their service users, promoting client-centred practice and making therapy meaningful and individually tailored. However, in practice, simply asking a service user what meaning an activity holds for them perhaps does not exploit the full potential of this concept.

2.2.2 The influence of context, culture and place on occupation

Thus far, the discussion has centred on a person-centred, one dimensional approach to occupation, inline with the stance of individualism, when in fact, it could be argued that the situation is far more complex (Hocking, 2000; Dickie, Cutchin & Humphry, 2006). A reminder is offered that people engage in activities within a socio-cultural milieu, which needs to also be considered. The individualist concept of occupation developed from the main theorists being based in the United States,
where individualism is central to the culture, which is likely to have influenced this. Instead, the idea that occupation always needs to be linked to context is proposed and that the larger experiential whole needs to be considered as well as the individual’s experience: the larger whole being other people and the social, physical and cultural context in which the occupation takes place (Dickie, Cutchin & Humphry, 2006).

With respect to this dualism of person and context, the context will undoubtedly influence the occupations of an individual. Yerxa et al. (1990) draw on Bertalanffy’s systems theory (1971) to offer an explanation. He proposes that the person is an open system within their environment and he/she absorbs the information in order to become more skilled. Individuals utilise occupations to achieve their goals. They do so by drawing on personal biological characteristics and the information processing systems they have developed, in the context of social and cultural expectations. One’s information processing system will develop through memory, learning and concept formation and shape how someone engages in occupation (Yerxa et al., 1990). The environment is multi-faceted, comprising of political, economic, sociocultural and geographic factors producing many different types of environments for individuals in differing circumstances (Hocking, 2009). It seems that these ideas are suggesting that people are learning, developing and forming concepts through their engagement in occupations, dependent on the context in which this takes place, which in turn influences future occupational engagement.

Furthermore, the social and economic environment will help determine which environments will be facilitative and which will be prohibitive, for example if there are good transport links to access desired occupations or if work opportunities and affordable housing exists in the local community. Marginalisation or social exclusion may result for some individuals if this infrastructure is missing to facilitate occupational engagement (Townsend et al., 2009). In light of this a danger is posed by the common misperception, that the limitations an individual might have in occupational engagement may be viewed as the problem of the individual. Instead it should be recognised that potential social, economic and political factors can be constraining: solutions become misdirected back to how the individual can cope (Rudman, 2013; Thompson & Kent, 2014), particularly significant if an individual acquires a disability. This approach lies at the centre of the biomedical approach to care and can be thus criticised.
Looking further at the socio-cultural environment, do people attach significance to the place in which the occupation takes place? It is proposed that there is an unconscious, highly individualist and taken for granted ‘being in place’ when engaged in occupation. People become comfortable and attach emotional significance to familiar places, such as home and social environments and cognitive schema become organised around the environments where occupations take place (Rowles, 2008, p128). This importance of place and occupation has been highlighted in occupational science research, with women (Sakuae & Reid, 2013; Shaw, 2009) and elderly people (Shank & Cutchin, 2010; Johansson et al., 2013), but not with rural spaces and ABI.

2.2.3 Occupation and the experience of being with others

So consideration has been given so far to two facets of occupation: the individual experience, plus the context in which it takes place. It could be argued that the dualist theory of person and context is still too simplistic (Dickie, Cutchin & Humphry, 2006; Cutchin, 2008; Frank, 2011). An additional layer to the influence of context on the individual is that of transaction occurring at the same time. The individual engages in occupations as a member of a complex social system and influences others around them and vice versa (Eakman, 2007). This is similar to John Dewey’s transactional concept of experience, which suggests that the person and their context are intrinsically woven together in the experience of the occupation (Dewey, 1938). The everyday experience of living is built up from the flow of daily occupations and relational experiences between person and contexts (Kuo, 2011), all presumably influencing how the individual is developing and being shaped in a particular way, in terms of attitudes, characteristics, skills and ideas.

2.3 Occupations impacting on the individual

2.3.1 Doing, being, belonging and becoming through occupations

Attention should perhaps now turn to how occupations impact on a person’s being in the world. Wilcock introduced the concept of doing, being and becoming and suggests that the doing or not doing of occupations impacts on personal health and wellbeing (Wilcock, 1998). Human beings achieve homeostatic balance and keep
well through successful engagement in occupations, indicating a three-way association of survival, health and occupation (Wilcock & Hocking, 2015).

This theory of doing, being and becoming is based on Maslow’s Hierarchy of Needs, where it is proposed that motivations come from the use of behaviour as a channel through which basic drives are expressed (Maslow, 1943). Here, the behaviour is synonymous with the engagement in the occupation, in order to express the basic drives such as survival and self-maintenance. The occupation also serves to meet intrinsic needs such as expression or fulfillment (Hammell, 2004).

People dream of future experiences and the occupations they hope to engage in, to create new environments. Maslow’s theory suggested that humans are motivated to set goals and move up the Hierarchy of Needs to achieve self-actualisation as part of life’s developmental process (Maslow, 1943). This notion of the future in what people are motivated to do is extended in Wilcock’s idea of doing, being and becoming, in that there is a cultural drive to be better at being and to become a different person through occupations (Wilcock, 1998, Wilcock & Hocking, 2015). This links back to Christiansen’s ideas of associating personhood and occupation; the subjective experience of the occupation leads to being a particular person (Christiansen, 1994).

But people engage in occupations collectively in groups, as well as individually and both, presumably impacting on the person. More recently the doing, being and becoming concept in relation to occupation has been extended to doing, being, belonging and becoming. This is an acknowledgement that the basic need of humans is to have a shared sense of place, family or community. People connect with others through shared occupations, bonds form, as do obligations to one another (Wilcock and Hocking, 2015). A sense of belonging can be achieved through occupational engagement with others, or by engaging in a solitary occupation that has a particular cultural form with which to feel connected to the culture. In order to belong to particular groups the norms of thinking and acting accordingly to this group will need to be adopted. For example, the person who belongs to a professional group might adopt its values and principles when engaged in occupations outside of this group too.
2.3.2 Occupation and meaning

Individuals ascribe personal meaning to activities and presumably this will influence which occupations they engage in. Linking back to Maslow (1943), occupations, stemming from basic drives, serve multiple purposes in the life of the individual. This includes survival, filling time or helping to reach one’s goals. They provide a playing field for change (or becoming) and can act as a mirror to the self or of the self (Carlson, Park, Kuo & Clark, 2012). However, the meaning of occupation in the lives of individuals is a complex phenomenon to understand, due to its subjectivity and not being readily observable (Nelson, 1996).

The role culture plays in constructing meaning in human action cannot be overlooked (Bruner, 1990). The meaning of the action, or occupation, is translated from the private sphere to the communal sphere through relating the action to the symbolic systems of the particular culture. Human life begins with a biological inheritance and is then shaped by what is going on around it: the discourse, patterns of community and symbolism (Bruner, 1990). The socio-cultural groups the individual is associated with will help shape this meaning.

One way to research meaning associated with occupation may be to conduct research with people who are no longer able to engage in their usual occupations and who are experiencing that loss. Indeed, it has been found that the meaning ascribed to occupations is multi-faceted: the occupation has a call, if it involves something the individual cares about such as responsibility; the occupation can mean being with others, and it can make connections with the past and the future (Reed, Hocking & Smythe, 2010). These findings do fit neatly with Wilcock and Hocking’s (2015) idea of doing, being, becoming and belonging, in terms of what occupations do and Bruner’s suggestion of meaning being transferred to the private sphere of the individual. Furthermore, the idea of the meaning of an occupation having a connection with the past and future is taken up by Kuo: she proposes that this ends in view aspect enables individuals to utilise occupation to create meaning in their lives (Kuo, 2011). This reinforces the ideas proposed in section 2.2.1 and the role occupations play in becoming a particular person.

Of course meaning in occupation will vary from individual to individual: this is what distinguishes it from activity. But does the meaning change for that same individual, at differing times and in differing spaces? And how do time and space influence the
meaning of an occupation and what cognitive processes are occurring to potentially explain this? Variations in time will occur across the life course, from birth, through childhood, adolescence and into the stages of adulthood. Meanings ascribed to occupations at different phases of the development will naturally exist. Variations in space may be of birthplace, where an individual goes to school, first employment, family home etc. People develop a cognitive map of these familiar places and contexts and gain an emotional connection to them, as well as the ability to go back to them in thought (Rowles, 2008). The space is much more than a physical location for occupations, and meaning is ascribed in terms of the culture and the social and political aspects that are apparent within that place (Cutchin, 2008). So, yes, over the course of time and in differing situations, individuals may well ascribe different meaning to the same occupation.

These ideas about meaning in occupation resonate with research from other disciplines about meaning in life in general. The phenomenon of creating meaning in life as a whole and also finding a connection with greater causes, was highlighted by the existentialist Victor Frankl, a holocaust survivor. He theorised that individuals manage to survive even under extreme adversity, by being able to choose one’s attitude to the situation (Frankl, 1946/2004). He suggested that people find meaning in life through the people they connect with, having experiences and by, ‘creating a work or doing a deed’, (Frankl, 2004, p115). It could be argued that Frankl’s ideas resonate strongly with Wilcock and Hocking’s (2015) ideas of doing, being, belonging and becoming through occupation.

2.3.3 Occupations and motivation to engage

So the arguments above claim that engagement in occupation has a personal and subjective meaning and is influenced by the communal space of a culture. Maslow’s theory and its links to motivation have been mentioned, but what additional considerations, if any, have been given to motivating factors to engage in occupations? Some researchers, outside of the disciplines of occupational science and occupational therapy, have approached the meaning of activity and motivation to engage in activity from the perspective of the quality of experience. It has been proposed that individuals are motivated to engage in activities that produce high quality experiences. Research suggests that some distinct responses are produced in people taking part in particular activities (Csikszentmihalyi, 1993). Ultimately, when engaged in highly challenging activities that require a high level of personal
skill a state of consciousness is reached described as flow. The concept of flow serves as an intrinsic motivation to engage in occupations to achieve this optimal experience (Csikszentmihalyi, 1990). It is defined as ‘the state in which people are so involved in an activity that nothing else seems to matter’ (Csikszentmihalyi, 1990, p4).

Csikszentmihalyi’s ideas suggest that individuals could be encouraged to undertake difficult occupational endeavours in order to develop personally, and achieve good psychological health. This could be critiqued in that many people avoid engaging in occupations they consider to be difficult, possibly due to lack of confidence, finding it too stressful or simply having an aversion to challenge. They may actually feel content within their current domain and be experiencing the state of nothing else seeming to matter whilst merely relaxing.

Other theories contrast why individuals are motivated to engage in particular occupations. Lewin’s early work on field theory proposed that behaviour comes about i.e. motivation to engage in occupations, due to the particular forces acting on a person at any one time. A dynamic field of co-existing forces creates a life space of which the individual and their psychological environment are part (Lewin, 1952, p25). Also, Bandura’s social cognitive theory suggests that behaviour is self-regulated, through forethought. This forethought for occupational engagement will be linked to one’s personal standards, the symbolic meaning of the occupation and the circumstances of the environment, as well as the likely consequences of engagement. In addition to this individuals are motivated by their self-efficacy or own perceived self-evaluation in achieving self-set goals (Bandura, 1991). If an individual is more likely to achieve, they are more likely to engage and will consider this before occupational engagement. In contrast, Csikszentmihalyi’s theory proposes that greater rewards will come from engaging in an occupation when it is a real challenge and suggests that motivation to engage is about setting goals not yet previously reached.

Further to this, self-determination theory developed the unitary concept of levels of motivation and considered differing types of motivation (Deci & Ryan, 2008). This theory suggests that motivation is autonomous, where an individual experiences self-endorsement or volition and the occupation’s value will be an integrated part of the self. Additionally, motivation is controlled: reward and punishment is taken into account, as are internalised factors such as potential shame, approvals and self-
esteem. The drives or needs are learned and are of variable voracity (Deci & Ryan, 2008). This appears to fit more closely with what Csikszentmihalyi is proposing, when high reward and increased self-esteem can be the result of highly challenging occupations.

So how do occupational theories address the issue of motivation? One occupational therapy theory to practice framework, The Model of Human Occupation (MOHO), seeks to offer an analysis of how motivation, the context and an individual’s skills are linked. The model explains occupational engagement in terms of volition (the pervasive need to act); habituation (regular patterns of behaviour guided by roles); performance capacity (the ability to perform the occupation) and the environment. Complex dynamics are produced from these four facets, which either constrain or promote the individual carrying out the occupation (Kielhofner 2008). The model underpins a number of standardised assessment tools for occupational therapy practice, making a clear attempt to integrate motivation, context and skills with treatment.

### 2.4 Habits and roles and forming the occupational identity

Patterns of occupation build to become habits and roles for individuals and a number of theories seek to offer an explanation of this and how this influences the individual’s being in the world or their identity.

#### 2.4.1 Habits and roles

If an occupation is repeatedly performed and done so automatically with limited variation it may become a habit (Clark, 2000). Habits are behaviours learned through childhood socialisation that are context-specific (Yerxa, 2002). Bourdieu proposed the concept of *habitus* in relation to performance in the social world. An individual’s habitus is a structured disposition that someone has been introduced to within the social and cultural environment of their world: it influences the person’s cognitive structures and motivates them to carry out practices in a particular way (Bourdieu, 1990). The habitus is individual to each person and influences the person to practice in the present in a particular way, dependent on their past experience of rules and norms. It does so through the formation of schemes of
perception over time, which produce particular thoughts and actions (Bourdieu, 1990).

Habitus is not only objectified in bodies but also institutions and social groups, to produce a form of capital that unconsciously influences action. If an individual from a different social group seeks to integrate in the group’s habitus it is likely that they will encounter difference, due to an alternative history of past experience and may find barriers to integration (Bourdieu, 1990). Presumably then, how someone acts, or carries out occupations, will be influenced by their habitus, due to cognitive schema held by the individual, that have been produced from their personal history and familiar environments. Bourdieu underpins his theory of habitus with the individual having a social capital from which to draw on. However, what has not been explored is how occupation contributes to capital, in order to further support successful engagement in occupations. This could accumulate within the individual, through the development of skills, cognitive schema and success of previous engagement.

The next consideration is how habits build to the concept of a role. Roles are ‘patterns of behaviour that distinguish between different activities within the group, and that interrelate to one another for the greater good of the group’ (Hogg & Vaughan, 2014, p299). They provide a subset of rules about how to act (Harré & Secord, 1972). An individual holds multiple roles in daily life. The expectation of how to engage in the role comes from the individuals themselves and externally from the group or society (Biddle, 1986). It could be argued that the role script is learnt during the process of engagement in the occupations associated with the role, amongst other things, such as observing others modeling the role and the group’s requirements of the role holder.

Also, roles prescribe an individual’s place within the group and what is the social expectation of someone in that role (Hogg & Vaughan, 2014). For example, within the family there may be an expectation that a mother will undertake specific activities, socially regarded as being gender prescribed, such as tending to personal care needs of children. This could be implicit within the functioning of the family or explicit through discussion on which family member will take responsibility for which task. Also, individual expectations of the role, possibly varying from social expectation of the role, will materialise, dependent on individual nuances coming from the person and their habitus. Social groups outside of the family that have expectations of a role could potentially be a community group or professional group.
Professional groups in particular, may have explicit expectations that define the role. There may be competencies and conduct expectations that are essential to abide by in order to hold that role. These groups constitute part of the social capital as described by Bourdieu (1990).

Thus the roles people hold influence the corresponding occupations they engage in (Kielhofner, 2008) and how they engage in these. Rayner (1995) describes a personal patterning of roles developing for each individual as they move through childhood into adulthood, with this patterning developing into an integration described as the adult identity. This can include sexual, racial, national, class and work identity (Rayner, 1995). Identity can similarly determine occupational choices (Abrahams, 2008).

2.4.2 Occupational identity

Habits and roles impact on the adult identity of individuals, as social beings engaged in occupations. Roles serve the purpose of maintaining social order by adherence to the norms of the social role (Jackson, 1998), for example someone’s role as an engineer, friend, husband, volunteer or policeman. Internalised patterns of action are required to fulfill those roles, which manifest in the socially expected behaviours associated with these, as well as the explicit behaviours, such as the professional behaviours mentioned above. The individual identifies with the behaviours and social expectations of the role (Kielhofner, 2008). Role related behaviours are explained by Identity Theory (Burke & Stets, 2009). Identity is defined as;

‘the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person.’

Burke & Stets, 2009, p1.

From an occupational perspective, an individual’s identity is closely associated with their engagement in occupations (Christiansen, 1999). At an early developmental stage the child learns that capability displayed within their occupations is compared to that of others within their social groups and social expectations are imposed. This constitutes the beginnings of the identity development with respect to group membership. The identity thus develops from engagement in occupations (Christianson, 2000). This relates consistently to Wilcock & Hockings (2015) idea of doing, (the occupation), being, belonging (social identity) and becoming (the
development and expectation). The common social question of “What do you do?” is typically answered by stating the type of paid employment engaged in, against which social judgement is made. However, this rarely offers clues as to the meaning that individual gives to their full repertoire of occupations outside of the worker role and in the rest of their lives and arguably it is more appropriate to think more broadly than work when considering occupational identity (Unruh, 2004; de Botton, 2009). Occupational science researchers have coined the term occupational identity to reflect this symbiosis between identity and the broad repertoire of occupations an individual engages in (Unruh, 2004; Abrahams, 2008; Asaba & Jackson, 2011; Christiansen, 2000; Kuo, 2011). Thus occupational identity is a composite sense of who one is and who one wishes to become, linked to roles, capacity, interests, priorities, routines, obligations and relationships (Kielfhofner, 2008). A positive occupational identity will potentially result from being occupationally competent (Christiansen, 1999; Kielfhofner, 2008).

It may be however, that the research underpinning this theory of occupational identity is skewed. Much of it focuses on occupations people choose to do, which may be influenced by research primarily coming from white, middle class societies of the western world. However, it is important to acknowledge that for many, dignified access to occupations is denied, for example where people live in dictatorships or where occupations are more focused on survival needs. In the western world limited access may still be apparent due to such as status, age, disability, race etc. The term occupational apartheid has been phrased to acknowledge this concept (Kronenberg, Algado & Pollard, 2005). This illustrates the possible impact of the sociocultural / political environment on occupational identity.

2.4.3 Occupation and work

Work has traditionally been seen as a primary source of occupational identity, with the work role linked to health and wellbeing historically and currently. In the sixteenth century the Protestant view developed that individuals could have the opportunity to portray the qualities of their souls, such as wisdom, kindness and respect and the medium through which to do this was work. Previous Catholic thinking was that these Christian virtues could only be portrayed in the work of the church. Attention shifted from what someone was doing in work to how they were doing it (de Botton, 2009). Someone thinking about how they complete their work
potentially encourages a display of creativity, building relationships or a taking of pride in the actual labour.

However, some two centuries later, The Industrial Revolution emphatically highlighted the idea that the new working practices of long hours toiling for mass produced goods led to some occupations being directly related to ill health and the sixteenth century ideal (arguably more in line with doing, being, belonging and becoming) had been lost. William Morris acknowledged that toil was necessary for existence to a degree, but condemned the poor factory conditions in which many worked as a curse: production and long working hours failed to offer ‘hope of rest, hope of product, hope of pleasure in the work itself’ (Morris, 1888, p2). A discrete absence of really producing something that mattered to the individual, was denying the man at work an exercising of the mind and soul, for the sake of creating material wealth for those above them in the social hierarchy (Morris, 1888). Along with John Ruskin, Morris led the promotion of the Arts and Crafts Movement, as a call for the re-engagement in craftsmanship, in the belief that it can restore the human spirit (Reed, Hocking & Smythe, 2013). Morris (1888) believed that true wealth was Nature itself, available to all. Wilcock (2001a) likens this to her occupation for health perspective, in that engagement in occupation should produce an alternative wealth i.e. good health. Thus today’s materialist culture might neglect the rewards from engagement in the occupation itself i.e. good health according to Wilcock, and the restoration of the human spirit according to Morris, by merely creating monetary reward.

Marx had proposed over forty years earlier than Morris (in 1843) that people became alienated from work if the purpose of work was merely to earn a wage for living, with the labourer’s time being used as a commodity: estranged labour results (Marx, 1843 / Livingstone & Benson, 1995). Morris’s creative activities gave the opportunity for a positive experience, whilst alienation from work might have lead to a destruction of the inner being and debasement (Wilcock, 2001a; Wilcock & Hocking, 2015). Thus being allowed to be creative at work or being able to consider how one engages with the work can reap intrinsic reward for the worker and this idea is in direct conflict with Marx’s view of the worker’s time being used as a commodity. In summary, Marx’s view was that working produced alienation from work (by being repetitive and exploitative) and Morris’s view was that if work allowed expression of creativity it allowed the individual to achieve intrinsic reward i.e. an alternative wealth.
The underpinning tenet of the alternative wealth of work has been explored in the Twentieth Century. Money earned allowed participation in the consumer society: advertisements for consumer goods courted the individual to part with their money for desirable items and they became caught up in a society of mass produced goods and having lost the pleasure in crafting and creating (Hodgkinson, 2007). This is the paradox of the consumer society with trading, ownership and wealth at its heart, whilst turning its back on art, nature and community (de Botton, 2009). Dant argues that modern day capitalist society ties people into social systems through the work culture and can deprive them of being able to realise themselves as individuals. Many individuals continue in work that they are alienated from, in order to maintain status and afford leisure pursuits (Dant, 2003). This suggests that the modern western culture can restrict individual’s becoming through occupation, by a focus on finding work that has monetary reward and status, as opposed to realising the self through a broader remit of engagement in occupation with alternative intrinsic rewards. However, what has not been explored is if an inner capital is built up within the individual through engagement in work, (similar to Bourdieu’s social capital), which may be drawn on to support other aspects of an individual’s life and their occupational engagement.

Flow Theory suggests that in order for an occupation to be satisfying, a degree of challenge above one’s capability must be experienced (Csikszentmihalyi, 1990). The link between what is satisfying to do and what is challenging to do has been questioned. The worthiness of the occupation should also be considered, in that for an occupation to be satisfying its value should be taken into account (Morgan, 2010; Christianson & Matuska, 2006). Furthermore, if individuals only sought high challenge occupations they could be at risk of burn out, which would counteract health and wellbeing. A mix of high and low challenge occupations, where calm, flow and satisfaction in occupations is achieved, is a necessary requisite for occupational balance (Jonsson & Persson, 2006). Linking this back to work, meaning and satisfaction within the workplace can come from a variety of sources, such as the practice of the work itself, financial reward, organisational culture and leadership styles, as well as how much individuals consider their lives to be in balance (Brown et al., 2001).

Even if paid employment does not bring satisfaction in the work itself, western society today has expectations around being employed and engaged in work. Also, unemployment has potential negative financial and psychological consequences.
(Brown et al., 2001) and may impact on being able to continue to engage in other occupations, such as leisure too (Deem, 1985). This may stem from the ideas of work being worthy and leisure something to be earned as a creed of morality (Morris, 1888). This can present a dilemma for those who wish to work but the socio-cultural environment does not allow the opportunity, for example with acquired disability.

Furthermore, work links back to occupational identity. Specific occupational identities are associated with being engaged in defined work roles. For example, development through specialist training and education can allow entry into professional work where individuals are respected for their knowledge and work with a degree of autonomy, examples being law, finance, engineering and health professions. Distinct subcultures in the workplace may develop which can involve jargon or the use of specific language, as well as professional beliefs, values and norms (Szymanski & Parker, 2013), almost suggesting what could be termed ‘professional schema’. The profession may possess particular traits and invest in controlling these as well as maintaining their distinctiveness from those of other professions (Armstrong, 1984).

But it must be remembered that the work role is only one part of the occupational identity, although possibly the dominant one. Many non-work occupations also help define occupational identities and roles, such as helping a child with homework as a father or mother (Dant, 2003), as discussed earlier, when considering the full repertoire of an individual’s occupations. However, a career ideal still exists with an upward trajectory of full time paid work carrying higher status (Taylor, 2004). Predominantly in the twentieth century work has tended to be understood from the dichotomy of leaving the home for paid work and remaining at home for domestic work: predominantly male and female roles respectively and thus influencing how work is conceptualised (Taylor, 2004), typified by stories such as Snow White and the Seven Dwarves, where the males left the house to do ‘the real work’ (Dant, 2003).

More recently there have been changes, with paid workers working from home and voluntary work being much more common. The work ethic of countries such as the UK may be an influence on the uptake of such as voluntary or unpaid work (Deem, 1985). A less skeptical argument may suggest that there may be personal satisfaction in engaging with voluntary work, such as being able to pursue a
personal interest or gain feelings of altruism. Indeed one large pan-European study with people in early old age suggests that engaging in socially productive activities, such as voluntary work is a strong predictor of improved quality of life. This may be due to factors such as gaining recognition and esteem from the reciprocal exchange of the occupation (Siegrist & Wahrendorf, 2009). A variation on this was found where the voluntary work involved caring for a relative, that was associated with lower quality of life, potentially due to less opportunities for social exchange and reciprocity due to the limitations this type of role can bring (Siegrist & Wahrendorf, 2009).

2.5 A balance of occupations for health

As well as the issues raised with respect to work and non-work occupations forming the occupational identity, an occupation-satisfied life also requires balance, with lack of balance leading to a feeling of overload (Hakansson, Dahlin-Ivanoff & Sonn, 2006), and potential impact on being healthy.

2.5.1 Occupational balance

Contemporary popular discourse is centred on establishing a work-life balance, originally focusing on workers with families to negotiate working conditions and access workplace support (Gregory & Milner, 2009; Veenhoven, 2009). Yet adopting a simplistic split into the dichotomy of work and life, fails to acknowledge the complexity of the multiple and complex domains of occupational balance (Backman, 2004; Christiansen & Matuska, 2006): such domains will be perception-based, according to an individual’s sociocultural values and expectations (Backman, 2004; Matuska & Christiansen, 2008).

So what constitutes the complexity of occupational balance? Certainly the lives of significant others impact on decisions made about how to balance activities, resulting in a social coordination of occupations, influenced by desires and expectations (Larson & Zemke, 2003). There may be gendered expectations about which member of the family holds certain roles e.g. the breadwinner, family carer or the one expected to fulfill household duties: this will vary across cultures. Beliefs about how to spend time acknowledging rituals such as birthdays and festivals and formalities about when to take holidays according to such as school holidays, are all factors in occupational balance and form a temporal habitus (Larson & Zemke,
An individual’s lifecycle stage may impact on occupational balance, as differing roles are associated with stages of the lifecycle: the presence of a significant other, children and the worker role may all impact (Singleton & Harvey, 1995; Christiansen & Matuska, 2006: Harvey & Singleton, 2009), especially if excessive demand is placed on the individual through this.

The work-life balance discourse tends to centre on people spending too much time in paid work occupations, leading to an occupational imbalance. However a lack of occupational balance due to having too few occupations, or having a weak temporal pattern of occupations can occur with illness or disability and result in low satisfaction in engagement in occupations (Eklund, Erlandsson & Leufstadius, 2010). Being required to give up paid work can occur as a result of ill health or retirement. People often find themselves with an occupational imbalance in terms of too much to do whilst in full time employment, only to find the opposite once paid work has terminated. Establishing regular commitments of a less intensive nature and slower pace can serve to overcome this dilemma (Jonsson, Borell & Sadlo, 2000).

It would appear therefore, that achieving a smooth, coordinated daily schedule of occupations is important (Larson & Zemke, 2003; Eklund, Erlandsson & Leufstadius, 2010), ideally involving the underpinning aspects of Maslow’s concept of self-actualisation, allowing for such as personal growth, autonomy and mastery (Christiansen & Matuska, 2006). Too few or too many occupations within the schedule will move the individual away from this desired outcome.

### 2.5.2 Occupation and health

Health and wellbeing are dependent on being able to engage in a balanced range of occupations. This relationship and indeed any apparent dysfunction or imbalance, is of interest to occupational scientists and occupational therapists: they seek to identify barriers to occupational engagement and promote participation (Wilcock, 2003; Conner, Wolf, Foster, Hildebrand & Baum, 2014). Individuals may not consciously understand the impact that their occupations have on their health and wellbeing, but occupational engagement serves to contribute to physical, psychological and social wellbeing, as well as linking to employment and status (Christiansen, 2015; Wilcock & Hocking, 2015).
The WHO proposes the following definition ‘health is a state of complete physical, mental and social wellbeing, not merely the absence of disease or infirmity’ (1946). Definitions of wellbeing emerged as early as the fifth century BC in Ancient Greece, when contrasting theories embraced both the total wellbeing perspective of the WHO today with engagement in occupation for health and a contrasting one, of a physiological theory based on the balance of the body’s fluids or humors. Opinions remain divided today, between those who embrace a broad definition commanding the expanse of sociocultural roles and responsibilities, in contrast to those who prefer a discreet medical perspective, making it easier to dictate where responsibility lies in maintaining health (Bickenbach & Glass, 2009; Christiansen, 2015; Wilcock & Hocking, 2015) i.e. through medical prescription and cure, a perspective that flourished after medicine became linked to germ theory and the development of biomedicine in the 1800s (Science Museum, 2015).

It could be argued that after the inception of germ theory, biomedicine took precedent over health through occupation, in that an illness could now be provided with a cure in many cases (though for psychiatry this came later and occupation still played a significant role in treatment). Thus occupation for health moved further down the agenda for maintaining health as biomedicine advanced, despite its clear place in restoring and maintaining health. Because the occupational therapy profession is based on promoting personal independence and growth, through personal responsibility, as opposed to a more paternalistic care model, it is philosophically aligned to the broader definition of health, with consideration of how one’s occupations influence health and wellbeing, as opposed to the biomedical approach of prescribing a cure for ill health.

2.6 Chapter summary

This chapter has developed the plot of the story of this thesis by way of introducing the concept of occupation and that all human beings engage in it. The differences between activity and occupation are highlighted, along with the importance of the context in which it takes place and the transactional perspective of occupation, suggesting that person and their context are interconnected through habitus. Wilcock and Hocking’s (2015) framework of doing, being, belonging and becoming is promoted as a basis for this understanding. Further discussion considers meaning, motivations to engage and how habits and roles form from patterns of
occupation. Occupational identity, including, but not exclusive to the dominant worker identity is introduced. The chapter concludes by discussing the connection between occupation and health yet its being overshadowed by the currently dominant biomedical approach.
Chapter 3              Narrated lives

3.1 Introduction to the chapter

“But they don’t talk to their dad. And I could see why. It’s the anger when he’s bursting like this. I have never seen somebody who can shout like that. And er I tried to find out when does, he does, this outburst. How, why and I er, and then erm, I got in touch with the charity. And they sent me books, information books and fact sheets, that I could read and relate to the symptoms. And you know how to handle it. And now erm, I could just see that my life had changed now. It wasn’t a romantic, romantic marriage that I was in. I thought it would be. (Laughs)”

This quote by one participant, Rita reflects how she came to realise that her ideas about her future life with her husband, Peter, would be quite different to what she had hoped: she married him without knowing that he had an ABI. Rita described the moment she realises the potential implications of ABI and the how it had impacted on her past with Peter, impacts on her present and will continue to impact on her future narrative. The structure of the narrative above jumps back and forth between the tenses.

This chapter considers how narrative is constructed within the minds of individuals; how the narrative changes in terms of past, present and future and in what way is it dependent on when the narrative is told, to whom and in what circumstances. Furthermore, it looks at what purpose the narratives serve within the psyche of the individual and how this links to identity and occupation as discussed in previous chapters. In order to develop the story format of this thesis in three Acts, the chapter considers the theories of the psychological processes engaged in the construction of narratives, what form narratives take, how narratives are expressed through the discourse and how narratives function to enable people to make meaning in their lives. For the purposes of this study narratives are synonymous with the oral production of personal stories in the social sciences, in order to study the psychological processes and social reality of the narrator (Schiff, 2012). They will be considered as a ‘kind of organisational scheme expressed in story form’ (Polkinghorne, 1988, p13).
3.2 The narrative mode of cognition

Of primary consideration is how the personal story or narrative is constructed within the mind of the individual. Three realms of reality constitute human existence: the material, organic and mental realms. Narrative functions within the mental realm, to influence an awareness of self through consideration of events that have taken place in the life of the individual (Polkinghorne, 1988).

Cognitively, the individual has two different ways of constructing reality (Bruner, 1986). The first is a paradigmatic mode of cognition, where we look for a simple and logical explanation and categorisation of concepts, related to one another, similar to scientific deduction and empiricism in mathematics, linked to an objective, positivist science. It is logical, testable, consistent and without contradiction (Bruner, 1986): the scientific viewpoint of the world. The second mode is a narrative mode of cognition, where a good story is formed with a more human quality, wants and needs expressed, influenced by where and when the action takes place. Human action and intention is considered with experiences of how people think and feel (Bruner, 1986). The former mode can produce an external, objective report for the natural sciences, whilst the latter can report on the realm of human meaning, of more significance in the human sciences (Polkinghorne, 1988). In the narrative mode action and consciousness combine to reveal psychic reality (Bruner, 1986). Human beings begin thinking in this narrative mode from such an early age that it becomes central and pervasive to their way of thinking (Murray, 1997). If this form of thinking is so apparent one wonders why it has not been extensively exploited in therapeutic applications from a psychological point of view? Application and research appear to be quite limited.

It is proposed that the narrative mode is not noting an accurate record of the world. Both conscious and unconscious forces are involved in the psychological production of a subjective narrative (Andrews, Squire & Tamboukou, 2013). The narrative thought processes are influenced by unconscious desires and conflicts (Schiff, 2012). Consciousness makes possible connections without considering if they can be proved or if they are true (Bruner, 1986). Physically identical happenings will deliver contrasting accounts from different individuals (Chafe, 1990), further influenced by the individual’s desires, their past and what they want to believe about the future (Bruner, 1990). A discrepancy often exists between how individuals say
they behaved and how they actually behaved, influenced by injecting personal meaning into the individual’s transaction with the social world, when expressed, whilst drawing on the narrative mode of cognition (Bruner, 1990).

The construction of the narrative is duly influenced in the mental realm. The mind is acting with creativity to produce a story, or narrative, influenced by the person’s cultural background and experience. The schema the mind holds influence the story, the schema having been formed by both the mind of the individual and the society or culture to which that individual belongs (Chafe, 1990). The schema are a part of knowledge that sees things as belonging together as part of an organised whole (Polkinghome, 1988), such as a nurse and uniform being part of the whole of a hospital ward encounter. It is this immersion in culture that allows individuals to express themselves in particular ways and in turn make meaning of their lives and connect with culture and its symbolic systems (Bruner, 1990). Such as an individual’s culture will influence the personal story as it develops within and the individual begins to see the person that they are, who exists and is placed within that same culture (Plummer, 2001).

If the scientific perspective is rejected in the construction of the narrative in the mental realm attention needs to turn to an alternative theoretical perspective that may apply. The social constructionist perspective is offered as an explanation of this by way of the narrative developing according to the cultural milieu and the contexts in which it is told (Murray, 1997), exemplifying the overlap of psychological and sociological factors impacting on the ‘psychosocial subject’ (Murray, 2015, p90). It can be likened to the idea of human life being shaped by walking onto a stage where a plot has already begun and the other actors already engaged with the plot and having an understanding of it (Bruner, 1990).

If the narrative in the mental realm is verbalised the narrator wants to project particular meaning from the story and constructs it in such a way as to influence that meaning. The narrator selects and connects events in a particular and partial way before verbalising them (Riessman, 2008). The disposition and characteristics of how people wish to be portrayed, such as a loyal friend or devoted mother are expressed and accomplished accordingly (Bruner, 1990; Schiff, 2012). The result is a dynamic and changing narrative mode of thought or cognition, with the individual having alternative positions available to them from which to draw: a reflection of the multiplicity of selfhood (Weatherhead & Todd, 2014). So integral to human thought
is narrative, that an ontological perspective of narrative is proposed: human beings
live in a story-shaped world and narrative is the means of interpreting personal
experience (Sarbin, 2005).

3.3 Meaning-making in the narrative

3.3.1 Emplotment

The narrative aims to persuade the listener to take away particular meaning from
the narrative. It is proposed that the narrative mode of cognition helps deliver a story
that generates a plot, which differs from a description of mere facts. The plot helps
to make the links between the events and reveals the meaning of the events from
the narrator’s perspective (Polkinghorne, 1995b; Goldie, 2004). The plot is a process
of integration (Ricoeur, 1991) and is independent of the facts or truth (Bruner, 1990;
Mattingly, 1998). It serves to inject emotion into a story, such as fear or concern, to
encourage the listener to engage (Riessman, 2008; Goldie, 2004). The listener is
drawn to follow the plot to discover how the story reaches its conclusion to
culminate in closure (Ricoeur, 1991).

Thus, if it is accepted that the narrative is not true to reality, it must be presented by
the narrator in such a way so as it appears to be plausible. The narrator,
incorporating their present position, facilitates this plausibility. By plotting the past
from the perspective of the present is to make a truth claim, by bringing the reality of
the past into the present time (Schiff, 2012). The fact that the narrative is told about
the past, from the point of view of the present, lends itself to this injection of
meaning, as the present perspective will be a new and different one: interpretation is
taking place at the same time as the narrative is constructed (Josselson, 2004). This
exemplifies the striking difference with the logical paradigmatic mode of cognition.

Analysis may reveal something of how an individual creates meaning of this
personal experience over time (Becker, 1997). The norms of the individual and their
cultural background will be tacitly revealed through the individual’s speech and this
is key to the power of the narrative (Wengraf, 2001). The story is also open to a
wealth of interpretation at both that point in time and in other contextual situations
(Ricoeur, 1991; Olsen, 1990). This potentially presents the opportunity to utilise
narrative as a window to the human condition in therapeutic settings, something that has yet to be extensively attempted.

3.3.2 Meaning-making and transaction

The canonical or ordinary state of being is utilised as a reference point in the meaning-making behind the narrative, to highlight how an individual’s story deviates from the norm or expected (Bruner, 1990). Mitigation is offered by the storyteller in order to negotiate the desired meaning (Bruner, 1990). They are able to put across their point of view by making the story compelling (Frank, 2010). Riessman reminds us that ‘stories don’t fall from the sky’, but are both constructed and heard in context (Riessman, 2008, p105). They are influenced by factors such as the relationship between the speaker and the listener, their social situation, culture, society and place in time, to name just a few (Riessman, 2008).

With the narrative being influenced by the relationship between speaker and listener, transactional processes will be taking place. The story is told as a social transaction and what is said and how it is said will depend on both the speaker’s choice of words and their deliverance of the detail, as well as how it is being received as told: it is a co-construction of meaning (Mattingly, 1998), involving negotiation between participants (Schiff, 2012). The listener plays an important part by way of the non-verbal cues and small utterances. This may determine how much detail the speaker decides to include: too much may bore the listener or divert the focus of the story, whilst too little could make the story fail to transmit the hoped meaning (Elliott, 2009). The narrator expects there to be a convergence of evaluation of meaning, by relaying a convincing account to the listener. However it may be that the listener forms an alternative evaluation of the events and their meaning, depending on how it is received and a differing emotional response to that hoped for may result (Goldie, 2004). Commonly the listener will demonstrate that they have received and accepted the narrative by commenting or telling a story of their own in response and in doing so it can indicate that the encounter of telling and receiving the narrative has made a difference (Brooks, 1994).
3.3.3 Temporal dimensions in meaning-making

Time impacts on the telling of the narrative, especially now it is being retold in the present and temporal dimensions are utilised to portray a convincing narrative account. Each story told yields two types of time from within. One follows the discrete succession of events and is infinite and open for the future. The second results from the emplotment and configuration of the story from beginning, to middle and drawing to the end, producing a closure on the succession of the story, like a poetic act (Ricoeur, 1991). A simple consideration of time as a mere succession of instances fails to acknowledge time as a dimension of human experience and the phenomenon of time as lived within the individual (Polkinghorne, 1988). This second form of time is a key feature of the emplotted narrative: it is told from the view of someone who already knows the endpoint of that particular story, by virtue of the fact that they are recounting past experiences. The cognitive process of the memory is different to the cognitive process of understanding in the moment, producing differing accounts: remembering requires use of the imagination, as opposed to perceiving to understand the moment (Mattingly, 1998). Furthermore, a revision of the past has taken place to coincide with what is known about the present (Polkinghorne, 1988; Charmaz, 1999).

Actual life as lived has no plot, but a narrator plots a story by recounting past experiences and linking these with a beginning, middle and end, a structure that is absent in life as lived (Mattingly, 1998). The narrator knows where to start their story because they know precisely where they intend to end the story and how the story ends: they tell it with a backward glance (Mattingly, 1998). There exists a ‘gestalt of human temporality’ where narrative serves to link the past and the future by the telling in the present (Brockmeier, 2000, p54). The interpretation is in the present context however and through this reflection a type of developmental story is produced (Schiff, 2012) viewed through the new lens of the present (Charmaz, 1999). A history of the self is formed in the narrative telling (Charmaz, 1999). This history of self will reveal a personal identity and potentially an occupational identity. If Brockmeier’s idea of linking past, present and future within the narrative holds true, it could suggest a potential for using the occupational identity in the construction of a hoped for future narrative.
Having considered narrative events as not necessarily being constructed in an ordinal manner, attention turns to how are they represented with respect to intervals of time. Time is distorted in that some moments will be prolonged in the discourse, whilst at the same time months, or even years, may be missed out entirely, if insignificant to the plot. Clock and calendar time are infrequently referred to in narrative (Brockmeier, 2000; Polkinghorne, 1988). The intensity of the story will rise and fall as determined by the narrator rather than as life lived. This distinguishes the lived experience of the present from narrative recollection (Mattingly, 1998).

The result is that only a partial picture of a whole experience is being recounted in the narrative (Ochs & Capps, 1996). People are selective in what they recount, which may lend the narrative greater consistency and coherence (Becker, 1997). This enables the narrative to appear more plausible but besides this desired outcome might there be alternative reasons to promote this coherence? The reason for this may be because the construction of a personal story contributes to the personal identity. Certain incidences may be omitted to coincide with the construction of an imagined future identity (Ochs & Capps, 1996). Silences or what is left unsaid within the narrative are highly significant: often this is a neglected part in the consideration of the narrative (Frank, 2006).

### 3.4 Modes of expression of the narrative

#### 3.4.1 Discourse as key to expression

Having discussed how narrative is part of an interaction, attention now turns to language utilised within the narrative, in terms of what function the language serves within the narrative telling. People reveal how they perceive the world through the use of language to express the meaningfulness of their lives (Polkinghorne, 1988). The language or discourse that carries the story influences the power of the narrative (Bruner, 1986; Polkinghorne, 1995). Language expresses the inner narrative and communicates meaning (Brockmeier, 2000; Hanninen, 2004). The language consists of much more than the words and sentences but also how it is imparted with verbal and non-verbal elements to constitute the discourse. The discourse is key: it is more than the words and sentences in that it constitutes integrated sentences that produce a global meaning or message (Polkinghorne, 1988).
The discourse can function as paradigmatic, to demonstrate logic; or narrative, to demonstrate meaningfulness (Polkinghorne, 1988). These two functions of the discourse relate to Bruner's (1990) two modes of cognition. The transaction with the listener is key and the narrator makes assumptions about the listener's understanding even though they can never know the mind of the listener (Bruner, 1986). All telling of the narrative is relational and this may need to be revised in telling to alternative people or in alternative environments (Eakin, 1999). One of the primary functions of the selected form of language in narrative is to persuade, in order to present the action and experience in a particular light: provocation is intended in that it may accomplish making the listener care (Mattingly, 1998).

3.4.2 Cultural symbolism in the discourse

The identity constructed by the telling is hugely influenced by the culture from which it originates. People learn as they grow up through family, school and work, how to present themselves as normal and how to present critical life events (Brockmeier, 2000). Attention must be paid towards much more than the specific linguistic content of the narrative, but also the way in which the narrative is performed in order to persuade (Mattingly, 1998), involving both verbal and non-verbal elements (Schiff, 2012).

It stands to reason therefore that the listener's psychological processes must be responding to interpret the narrative they hear. So in which way might this be taking place? Interpretation of the narrative is dependent on the symbolism inherent in a culture's system of signs, so as the listener understands what the language used 'stands for' (Bruner, 1990, p69). As children learn language skills they develop a sense of how to use them to invoke meaning, over and above the actual words themselves (Bruner, 1990), for example 'no smoke without fire'. The meaning of the narrative becomes located within the discourse (Mattingly, 1998). Therefore if the narrator is inherently using their identity to construct the discourse, analysis of the discourse may reveal the identity. The standpoint of the interpreter could perhaps be exploited to select particular elements of the discourse, for example an occupational therapist could potentially select the occupational elements to utilise them in therapeutic interventions.
3.5 Narrative form

3.5.1 The cultural stock of stories

We live our lives in narrative, remembering, believing and planning in narrative form and draw on the narrative script to make meaning of our lives: we do this by relating our narratives to the stock of stories that surround life (Widdershoven, 1993). Tradition has developed a sedimentation in people’s minds of ways of emplotting stories that go on to become transmitted in the narrative (Ricoeur, 1991). It is proposed that the mind builds models of the world in these different ways, firstly from basic sensory input, but in addition to this it clearly continues to build models in the absence of further sensory input, for example constructing representations in dreams (Chafe, 1990). Pre-prepared schema held in the individual mind will both guide and constrain this process of plotting and interpreting the narrative, formed from culture, for example from ideologies, a profession or system of education (Chafe, 1990). Each person’s model-building will thus be quite individual (Bruner, 1986; Chafe, 1990). These ideas support the alignment of narrative with a social constructionist perspective.

The literature of a culture plays a significant part in this. A number of narrative theorists support this influence. Literary stories provide different meaningful patterns of the way in which people have lived their lives, against which the reader measures if the life of the protagonist has been adequate or has lived up to ideals (Widdershoven, 1993). People become compelled by stories due to the psychological processes helping them identify with certain characters, representative of the range of characters carried within the unconscious (Bruner, 1986). Current stories are echoed in the form of past tales, producing resonance (Frank, 2010). Literary history, as far back as Aristotle and the Ancient Greeks, recognises the three story genres of epic, tragedy and comedy, each having beginning, middle and end within them (Ricoeur, 1991). Frye’s literary criticism suggests that stories in European writings are formulated as either a tragedy, comedy, romance or ironic, centred on the hero’s (or main protagonist’s) power of action (Frye, 1957).
3.5.2 Narrative plot lines and genres

Earlier it was discussed how the individual constructs their narrative in order to shape reality. This links to the idea of literary stories influencing narrative form from a social constructionist perspective. Within literary criticism it has been argued that western autobiography typically produces the ideal storyline of the heroic myth, where the main protagonist becomes embroiled in the beginning-middle-end storyline, eventually triumphing over adversity (Campbell, 2008). This is a typical plot to personal stories too. But whilst this may be accepted as a believable storyline for a male, it can present a less believable one for a female, as it is argued that the cultural stock of stories holds few of these for females to emulate. Typically female stories are stories of relationships, portrayed as fulfilling the wishes of others, such as a father, as opposed to being able to make a believable claim to wishing to fulfil their own happiness (Gergen, 1994). Established social narratives may lead a narrator or listener to anticipate an ordered account of the events, or complete a narrative in a similar vein as the social narrative (Murray, 2015). Certain narrative forms dominate particular institutions, such as courts of law or hospitals: not conforming to these styles can render the narrator misunderstood or incompetent (Riessman, 2008).

This argument can be developed further, if narratives of people becoming seriously ill are considered. Arthur Frank’s studies of illness narratives led to the proposal of three dominant illness narrative types: the restitution narrative using language of survival; the chaos narrative as its opposite, where illness cannot be remedied and the quest narrative where the narrator holds a belief that they have learnt from the illness journey (Frank, 1995). His later work revised this brief list of three to include alternatives: the life as normal narrative, where illness is not discussed so as to preserve living by other narratives; the borrowed story narrative, where narratives are shaped from tales of childhood and the broken narrative which has to rely on another person to tell the narrative due to the physical or mental incapacity to tell one’s own narrative (Frank, 2013). This is a genre approach to analysing narratives and other approaches may equally well offer useful interpretation. For example, an occupational analysis may offer clues as to the occupational identity of the narrator.
3.5.3 Psychological perspectives

It is claimed from a psychoanalytic perspective that folklore and fairy tales are influential in the development of this unconscious form of narrative structure in the psyche, (to produce the borrowed story narrative as proposed by Frank) (Cashdan, 1999). This is thought to begin as children engage with early storytelling activities (Schiff, 2012). Children become enthralled by fairy tales during significant points in their psychological development: they identify with struggles in their own developing relationships through the tales (McAdams, 1993; Cashdan, 1999). The four-part journey of the fairy tale; crossing, encounter, conquest and celebration, becomes part of an ingrained narrative structure that can bring triumph and transformation and is thus unconsciously assumed to be a natural or desirable narrative structure for life (Cashdan, 1999). A cultural transmission of imagery takes place throughout the individual's development, due to exposure to stories and family dynamics, pervading the unconscious mind of the adult. By the time adulthood is reached a stockpile of imagery has accumulated to leave a host of personalised symbols and fantasies (McAdams, 1993), all serving potential formats to personal storylines. An expectation results that life will unfold according to certain plots (Frank, 2010).

Cashdan's ideas above, do carry some weight within social constructionism too, aside from the development of the individual psyche, in that the type of stories produced by a culture at any one time will depend on the culture's own stage of psychosocial development (Polkinghorne, 1998). In order for the narrative to be adequately received it must fit with the current cultural stock of stories about what constitutes a reasonable life. One significant proposal is that the narrative form follows either a progressive, regressive or stable format. From what has been previously discussed, the end point of the story should be advancing towards an end point or achieving a goal: a progressive narrative will achieve a success; a regressive one end in loss or failure and a stable one exhibits no change (Gergen 2009).

McAdams considers the characters by which individuals represent themselves in the narrative as being agentic or communal. The agentic character is associated with the male gender stereotype of being able to overcome, master and win: the warrior, the sage, the traveller and the maker. In contrast the communal characters are more associated with relationships and the female gender stereotype: the lover, the
caregiver, the friend and the ritualist. These characters seek relationships and are not necessarily female, but demonstrate feminine characteristics (McAdams, 1986).

The influence of the narrator’s formative years is a theme explored in the development of the narrative tone that comes to be expressed in life stories. Individuals are ‘collecting material’ about themselves and their experiences from birth onwards, which serve to shape this (McAdams, 1993, p46). Forming a secure attachment in infancy can leave a legacy of hope and optimism in life and strongly influence the narrative tone towards being optimistic in adult life. The converse would suggest that the adult might reflect a pessimistic narrative tone, if such an attachment were not made at a young age (McAdams, 1993). An optimistic narrative tone may pervade a story formed as a romance or comedy and a pessimistic narrative tone pervade a tragedy or irony (McAdams, 1993). However, it could be argued that it is possible to form secure attachments in infancy and experience a series of tragic life events to result in a pessimistic narrative tone and research as to the accuracy of McAdam’s theory is lacking.

3.6 Narrative and identity

3.6.1 The relationship between narrative and identity

The link between narrative and identity has been introduced but is now explored further. Socio-narratology theory proposes:

‘stories give people the resources to figure out who they are, and how stories both connect and disconnect people’

Frank, 2010, p71

The preferred term is narrative identifying to reflect the idea that the identity is never a finished project and possible identities continue to be available to people (Frank, 2010, p49).

Further theoretical development has been offered around the function narrative plays in the construction of identity, where the individual is viewed as this ‘self’ changing through the medium of discourse, as opposed to the humanist / modernist proposition of an enduring ‘self’ and essential identity (Elliott, 2009). Participation in the drama-shaped world leads to identity formation (Sarbin, 2005). Stories are told
to reveal to others who people think they currently are (Mattingly, 1998) or the self-image they hope to convey to the listener (Hydén, 1997; Schiff, 2012). They are the self’s ‘medium of being’ in the world and help to find new destinations of where to be or go (Frank, 1995, p53). This is similar to Bruner’s idea of ‘possible lives’, where the autobiography develops over time (Bruner, 2004, p694) and Wetherhead & Todd’s (2014) multiplicity of selfhood, as part of the lifelong ceaseless process of forming the identity (Eakin, 1999).

The identity is formed from the relationship between the lived experience and the way in which this is articulated in story form (Widdershoven, 1993), projecting a particular image of self, both internally and externally (Funkenstein, 1993). Through this the self becomes located in life (Charmaz, 1999). The self becomes located with others through relationships with the stories, aiding an understanding of self by narrating with others. The aim is to become the self as anticipated in the inner story, held in the mind of the individual. This requires rejecting stories along the way that fail to match the inner story (Frank, 2010).

3.6.2 Narrative and social identity

People strive to accomplish their identity in the narrative through the performance (Riessman, 2008). As life is lived and major events experienced a psychic reorganisation takes place in the minds of individuals through reflexive processes (Giddens, 1991). Furthermore, as culture changes over time new public narratives are proposed, which serve to offer the individual new opportunities to reinterpret the self-understanding and narrative identity (Ricoeur, 1991) and presumably revise the inner story. If established cognitive schemata are apparent in the mental realm of the individual, these potentially mix with the telling of cultural and public narratives.

Having considered narrative identity as personal identity consideration turns to the individual within social groups and the social identity. Most individuals connect to a variety of social groups or through a number of social relationships, each of which brings out differing narrative identities for the individual, coherent with that particular relationship (Frank, 2010; Murray, 2015). Social groups carry narratives too: identifying with the group narrative can lead to cohesion of the social group (Riessman, 2008), one example of the ways in which stories can serve to connect people (Frank, 2010). The place or scene of narrative events may influence identity too. Social relationships are encountered in context, with where the event took place
being central to it. This idea suggests concept of place identity developing from the narrative (Sarbin, 2005), where individuals may experience an affinity with place, for example urban or rural.

The narrative can serve to seek validation of an identity claim (Murray, 1997). This image of self relies on the narrative imagination, not only by imagining the identity one has, but also by imagining alternative rejected identities (Andrews, 2014). The narrator has the opportunity to display (or reveal) a character (Frank, 2010). Identity development links this myth-making within the mind of the individual, to the stages of psychosocial development: the transition from adolescence to young adulthood is a key stage for the development of the main character (or self) in the personal narrative. However, the main character may be a synthesis of a number of competing images, which if resolved produces the mature identity. With all good stories being in need of a satisfactory ending, the mature identity will be attained and leave something of importance passed on, by way of some form of legacy (McAdams, 1993).

So how does narrative identity impact on an individual with unresolved psychological issues? This ceaseless forming of the narrative identity is both a subjective one and dynamic one, changing over time and being continually revised (Ricoeur, 1991). A retrospective revising and reordering of past experiences to coincide with the present condition provides a coherent and often aesthetic version of the self. If a complete story of self cannot be formed the personal identity remains incomplete, potentially resulting in unhappiness or despair (Polkinghorne, 1998). If negative narratives of the self predominate the plot of experience will serve to form a deficit identity (Prosser, 2009). Furthermore, the inability to construct a future story of the self and projected identity can result in loss of hope (Polkinghorne, 1998).

### 3.7 Chapter summary

This chapter has continued to develop the thesis as a three-act story and introduced the concept of narrative being part of a cognitive process, distinct from logical scientific thinking, by way of the inclusion of a plot and meaning making in the discourse. Social constructionist perspectives of the ways in which culture influences the narrative mode of cognition to produce the narrative are introduced, including the contribution played by literature in this. How language influences
narrative form is explored, as well as the inextricable connection between narrative and the shaping of identity.

Having discussed previously (Chapter 2) how occupations and identity are linked, it thus follows that if narrative has a place in shaping identity, a clear link between occupations and narrative is apparent: narrative is the way in which the experience of the occupation is understood. The individual’s unique identity is achieved through engagement in occupation and the meaning-making in the engagement is expressed through narrative. Shared meaning can be realised through groups of people collectively engaged in occupation, such as within a profession (Christiansen, 1999).

The meaning derived from different occupations, as told through the narrative, could potentially be developed to make clearer connections for occupational therapists to analyse how occupations impact on health and wellbeing. One approach to researching this would be to explore the meaning of occupations by listening to their narratives of engagement.
ACT II Obstacles encountered

Chapter 4

Disruption of occupations and the narrative with acquired brain injury (ABI): the person with ABI and significant others affected by the brain injury

4.1 Introduction to the chapter

“So er, I was in hospital for a good month I think it was. After that and then they discharged me and didn’t really tell me anything about you know what might happen afterwards. It was just a case of “You’re well enough to go home now. Bye. …” And er, after I got home I sort of started experiencing memory problems and had panic attacks er cos I didn’t know where I was or what anything was. Erm, couldn’t recognise erm family members and things.”

This quote reflects the initial disruption to the narrative of participant, Angie, on discharge from hospital following her ABI. Angie was eighteen at the time and her injury was acquired from an infection, encephalitis. She told her life story as a participant some twenty years later and the facial recognition problems (proposagnosia) and other symptoms, continue to impact on her daily life.

Not only is narrative disruption a phenomenon for the person with the ABI but it may also be exhibited in people closely connected to them (significant others (SO):

“So eleven o’clock he wasn’t up here. So I rang him. I says, “What’s the matter with you?” “Nothing the matter with me.” I says, “Oh but there is Gordon.” I says, “You never go this long in a day without being up here” “I’m coming up now. I’m just watching the television.” And when he came up I says, “Don’t you ever dare do that to me again.” I says, “You can go where you please as long as I know where you are.””

This quote comes from one participant, Diana, whose son Gordon experienced a brain injury due to a car accident at the age of twenty-two. She lives separately, but in the same rural village as him and some seventeen years later is still anxious about his day-to-day welfare.

Having considered in Chapter 2 how a balance of occupations can impact on health and identity in general populations, and in Chapter 3 how this links to the way in which individuals construct narrative in their lives, consideration turns to individuals whose life becomes disrupted by ABI and how the relationship of occupation, identity and narrative is subsequently affected. In terms of the thesis being
presented as a three-act story, this chapter is the first in Act II, when the plot complicates and issues begin to arise for the characters concerned.

4.2 Occupational disruption for people with ABI

The experience of any injury or disease can limit access to an individual's previous and established repertoire of occupations, leading to an occupational disruption. The cause may be due to not being well enough to engage, or being unable to access opportunities that were previously open to them. When acquired unexpectedly, disability can bring unanticipated and unwelcome change, such as physical or psychological impairment. Older people who have experienced declining health over time may negotiate this change accordingly (Griffith, Caron, Desrosiers & Thibeault, 2007) through the stages of psychosocial development. Acquiring an illness or disability prior to old age may be different and is associated with a period of transition in order to re-establish occupational balance (Lund, Mangset, Wyller & Sveen, 2015). Limitations may be presented at a level far outside the influential sphere of the individual: external restrictions on occupational engagement or participation are found when social policies are not constructed to enable people with disability to feel part of the whole community and may lead to limited societal engagement. Additionally, a dominant negative disability discourse can lead to attitudinal barriers to occupational engagement (Nicklasson & Jonsson, 2012). Individuals may feel marginalised and see being socially excluded as an occupational threat, in that activities are very much restricted (Lund, Mangset, Wyller & Sveen, 2015).

Occupational disruption following ABI is first experienced during transition from hospital to home. There is a frustration to regain independence and successful occupational engagement, due to symptoms of fatigue accompanied by slowness (Turner, Ownsworth, Cornwell & Fleming, 2009). This may be due to individuals being no longer able to successfully gauge their level of occupational performance at this early stage and have few opportunities to test this to find out. This issue can be compounded if the individual lacks insight into their capacity, which does commonly occur (Conneeley, 2004). Incongruence may exist between what an individual believes they can do and what they can actually do, relying on pre-injury performance as a yardstick.
Time since the injury appears to be insignificant with respect to occupational re-engagement, even when some physical or cognitive recovery has taken place (Eriksson, Tham & Borg, 2006). This would suggest that the picture may be complex and that occupational engagement post-injury may not only be related to factors such as severity of injury as first assumed. Levels of occupational disruption have been found to be independent of factors such as the individual's age and gender (Curtin et al., 2011).

The severity and symptoms of an ABI vary enormously, leading to no two experiences being identical. For individuals specifically with memory impairment following ABI, a chaotic life world may be initially experienced, with a lack of coherence in unfamiliar and unplanned situations. Engagement with familiar activities can help to re-create inner pictures to restore this in both familiar situations and new life situations (Erikson, Karlsson, Borell & Tham, 2007). Achieving successful occupational engagement is a long-standing issue for those with ABI, with a resulting major impact on the individual's doing, being, belonging and becoming.

### 4.3 Occupational identity and ABI

There are consequences of occupational disruption in terms of the occupational identity. A key theme from published research in this area is the link between still being able to engage in occupations and maintaining or striving for an occupational identity (Alsaker & Josephsson, 2013; Blank, Harries & Reynolds, 2015; Nayar & Stanley, 2015). Forced withdrawal from occupations can impact on both identity and life roles, potentially leading to a loss of self-worth and self-esteem if challenged (Preston, Ballinger & Gallagher, 2014). Occupations are grounded in personal history and following illness or disability need to be renegotiated by way of adaptation, loss or replacement. If an individual's health status is unpredictable on a day-to-day basis, as may well be the case, occupational engagement will be disrupted both in the present and prediction for future engagement becomes uncertain (Alsaker & Josephsson, 2013). Furthermore, identity issues are often managed by how much is revealed about identity status to others to avoid becoming labelled (Olney & Kim, 2001).

Individual's routines and habits are disrupted as a result of ABI (Hoogerdijk, Runge & Haugboelle, 2011). Several can remain unsuccessful even several years post-
injury, such as sleeping and driving (Plach & Sells, 2013); activities that involve social contact (Winkler, Unsworth & Sloan 2005); education (Plachs & Sells, 2013); relationships (Eriksson, Kottorp, Berg & Tham, 2009); and work (Hooson, Coetzer, Stew & Moore, 2015). One study, specifically with individuals who had experienced a stroke, suggests that restrictions are placed on the individual’s occupational world with respect to the range of occupations, who they do occupations with and where they take place (Laliberte-Rudman, Hebert & Reid, 2006).

Potential occupational identity issues emerge for individuals with ABI in a number of ways. An understanding of the self (in this case a new self) may not be apparent and occupational engagement can be suddenly compromised (Bryson-Campbell et al., 2013; Nalder, Fleming, Cornwell, Shields & Foster, 2013). The formulation of a new self-concept has been suggested as being key to adaptation but a new occupational identity and adjustment may take considerable time (Klinger, 2005; Hoogerdijk, Runge & Haugboelle, 2011). The self-discrepancy between pre- and post-ABI identity has been explored from the theoretical perspective of acquiring the post-ABI identity being similar to a grief reaction. One study found affective distress was indeed linked to self-discrepancies around identity (Cantor et al., 2005).

Similarly, negative changes in self-concept following brain injury are associated with depression and grief (Carroll & Coetzer, 2011; Ponsford, Kelly & Couchman, 2014), and poorer self-concept being associated with a lower quality of life (Vickery, Gontkovsky & Caroselli, 2005). A return to the perceived pre-injury ‘normality’ is frequently not an option and life becomes viewed more in terms of ‘moving forward’, with issues of changed status and identity to be addressed (Conneeley, 2012, p81). Such a reformulation over time links to the importance of being as a form of doing (Stone, 2005). When functional recovery has reached a level where little improvement is continuing, identity issues may well persist and impact on mental health and present as depressive symptoms (Cotton, 2012). Having made the connection here between occupation, identity and narrative it is surprising that a narrative approach to rehabilitation rarely occurs and a biomedical or biopsychosocial approach predominates.

Suggestions have been made as to how such issues might be expediated or remedied. It is proposed that such limitations may be progressed by actual engagement in new occupations (Erikson, Karlsson, Borell & Tham, 2007; Hoogerdijk, Runge & Haugboelle, 2011), rather than relying on a return to previous
ones. Similarly feedback from engagement in occupations may be of assistance in helping recover self-awareness of abilities (Dirette, Plaisier & Jones, 2008).

Re-establishing old or new forms of occupational engagement (occupational adaptation) is a way of negotiating this identity change (Asaba & Jackson, 2011; Blank, Harries & Reynolds, 2015). Everyday occupations, like work, have been found to connect people to their personal values and interests and to feel socially connected. Thus, it could be argued that it is an essential part of being human (Asaba & Jackson, 2011; Blank, Harries & Reynolds, 2015). If occupational adaptation is successful it can open up the range of occupational choices to individuals and can be seen as a proactive strategy in adjusting to the new situation, even though it may require accepting a replacement, rejection of some former occupations (Nayar & Stanley, 2015) or accepting some form of compromise.

This post-injury situation illustrates that typically individuals with ABI are no longer able to engage in occupations in the same way that they did pre-injury, which has an impact on self-concept and identity (Hoogerdijk, Runge & Haugboelle, 2011), requiring an adaptation process that is not always achieved. This may be explained by the fact that elements of the previous life circumstances are still a part of present circumstances: the pre-ABI identity has not disappeared and a post-ABI identity has not been fully accepted. Moving to an acceptance of the new identity is dependent on a person-specific repertoire of occupations, within an individual adaptation process (Hoogerdijk, Runge & Haugboelle, 2011), with implications for traditional rehabilitation approaches, where perhaps the focus could be more person-focused and incorporative of identity issues (Heller, Mukherjee, Levin & Reis, 2006; Muenchberger, Kendall & Neal, 2008; Carroll & Coetzer, 2011). One meta-synthesis of qualitative research strongly supports the idea that recovery is associated with a re-construction of identity post-ABI (Levack, Kayes & Fadyl, 2010). However, what is lacking from the research is rehabilitation techniques that take into account the capital built up from occupations pre-injury and using this in identity construction post-injury that has the potential to aid recovery.

Further research has reinforced the link between occupation and identity, exploring how individuals with ABI make sense of themselves post-ABI. One study (Gracey et al., 2008) approached this from a cognitive psychology perspective and produced some interesting results. Sense making was not found to be in terms of impairments or abilities, but neither was it simply on the basis of participating in activity or being
socially engaged. The *meaning* and *felt experiences* of taking part in social and practical activity were key (Gracey et al., 2008). If consideration is given to Chapter 2, where the difference between activity and occupation was explored, it was proposed that occupation is the experience an individual has whilst taking part in the culturally defined idea of that activity (Pierce, 2001) and linked to the individual’s personhood (Christiansen, 1999). It would appear that Gracey et al. are suggesting a similar phenomenon.

### 4.4 Social integration issues following ABI

With identity being comprised of the elements of personal and social, social identity might be compromised long term. The ease of established friendships being maintained or new ones formed is now challenged. Community reintegration has been found to improve 1-3 years post injury, when measured against how integrated individuals had been at three and six months post injury (Willemse-van Son, Ribbers, Hop & Stam, 2009). However, this would be expected and does not indicate how close these measures were to pre-injury levels of integration, although all were found to be lower. Patterns of integration have been reported to continue to improve even after three years post-discharge, but overall levels have continually been revealed to be poor. Achieving acceptable lifestyle reintegration following a return home from hospital, may occur for as few as 22% of individuals, even at the five years post-injury stage (Doig, Fleming & Tooth, 2001) and it is suggested as even longer by others (Johansson, Hogberg & Bernspang, 2007).

There is a possible explanation for such low levels of integration and the family may be called upon to compensate for this. It should be borne in mind that pre-injury individuals may have focused on vocational activities and had little time for community integration that they now seek post-injury and bridging that gap can be harder with ABI, especially where there has been a negative impact on the individual’s personality. Voluntary relationships such as friendships (as opposed to family relationships), can become vulnerable and difficult to maintain and / or initiate, except for friendships with others who have an ABI (Nichols & Kosciulek, 2014). Where social contact has reduced it can be of the individual’s choice post-ABI, due to the lack of tolerance and understanding they experience from others in the community: the master status of *head injury and disability* can override all others (Conneely, 2002). Compounding issues can be fatigue, communication difficulties, public misconceptions of being aggressive and memory impairment affecting
autobiographical memory, which is required for successful interaction with others (Conneeley, 2002). Withdrawal from social environments may also be due to physical limitations leading to feeling less in control as a result, or an unwillingness to engage in previous successful activities in a less proficient manner (Robison et al., 2009). The result in some situations may be that the individual is reliant on significant others within the family for their social occupations and may otherwise be isolated (Lefebvre, Cloutier & Levert, 2008).

4.5 Work disruption for people with ABI

As work is the main occupation of younger and middle-aged adults, a change to work has the potential to be the major source of occupational disruption (Soeker, 2012; Forslund et al., 2014) and disruption of occupational identity. Success can depend on the rehabilitation support programmes available and specialised brain injury vocational rehabilitation programmes have shown significantly better results compared to those receiving usual care: 15-27% more of individuals (dependent on severity of injury) successfully returned to either work or education (Radford et al., 2013).

One would expect to be able to identify a number of factors impacting on the long-term success of maintaining a worker role. It is suggested that there is a relationship between an instability in employment and the severity of the injury, as may be expected (Soeker, 2011; Forslund et al., 2014). Many require a change of employment due to inability to cope with former work demands (Van Veltzen, Van Bennekom, Edelaar, Sluiter & Fings-Dresen, 2009). A job demanding lower levels of qualification than the one pre-ABI is more likely to result (Bonneterre et al., 2013). Good emotional and social functioning, as well as relatively intact metacognitive skills is associated with more successful return to work. In addition to this, self-awareness and being able to adopt learning strategies helps with re-integration into the workplace, suggesting that the pre-injury personality may be an influencing factor (Lundqvist & Samuelsson, 2012).

If one were to consider this from a bio-medical perspective, being no longer able to complete former work tasks due to impairments would necessitate a change of employment. However in one qualitative study, when people with ABI were asked about their return to work, understanding and support from the employer and colleagues was seen as crucial to success (Rubenson, Svensson, Linddahl &
Bjorklund, 2007). This suggests that a biopsychosocial approach may be preferred, where the environment adapts for the individual and offers more chances of success, factors identified by Kirsh et al., (2009), who suggest the importance of a *person, environment, occupation fit*. A significant part of this is having a supportive workplace (Shames, Treger, Ring & Giaquinto, 2007; Lundqvist & Samuelsson, 2012; Bonneterre et al., 2013). Success would allow an individual to maintain their occupational identity and preserve their sense of occupational history and hopes for the future, which is often compromised in such circumstances (Conneeley, 2012).

To summarise, it would appear that there is a very complex interaction between factors influencing return to work, such as pre-ABI personality, level of injury, personal and contextual circumstances, which together make prediction of success in return to work extremely difficult (Shames, Treger, Ring & Giaquinto, 2007).

Although returning to work for many can be a high priority, typical anxieties and concerns exist for an individual with an ABI when preparing to re-engage with the workforce. It is suggested that individuals may have concerns about potential attitudinal barriers and prejudice. Non-visible impairments such as fatigue and cognitive deficits may be poorly understood by fellow workers, misinterpreted and contribute to the attitudinal barriers and prejudice. The individual themselves may not be fully aware or be able to gauge the new-found level of competence (Conneeley, 2012), thus further complicating the personal interpretation of the performance in the workplace. It is suggested that return to work is more successful if individuals make their employer aware of non-visible impairments and if employers are more willing to be supportive of them (Bonneterre et al., 2013).

Post-ABI work is prioritised in new ways too, sometimes being less meaningful now that existential questions in life are being raised (Johansson & Tham, 2006; Rubenson, Svensson, Lindahl & Bjorklund, 2007). One study that tried to establish if there was a connection between working post-ABI and life satisfaction found no relationship between the two (Johansson & Bernspang, 2003). When considering any ABI research however, small or large scale, what needs to be taken into account is a common lack of homogeneity in participants, primarily down to the variety seen in ABI.
4.6 Occupational disruption for significant others in the lives of people with ABI

As ABI not only impacts on the individual who sustains it attention now turns to significant others whose lives are impacted by the ABI. There is less research on experiences of significant others, such as family members of people with ABI, though there is some. Much of the published research focuses on the psychological affects of being in the role of caregiver instead. There may be a dislike and offence caused by the term *carer* with a preference for people being described within their regular role e.g. parent (Lee et al., 2001). The dominant theme of research in this area presents as stress and burden through the significant other taking on the role of carer, as opposed to being researched from an occupational perspective. Carer strain may be apparent in as many as 42% of caregivers. However, no predictive variable has been found to be associated with this (Boycott, Yeoman & Vesey, 2013)

4.6.1 Stress and strain in the caregiving role

Stigma and discrimination may be associated with the caregiver role and resulting mental health outcomes may then impact on the quality of care (Phelan et al., 2011; Jumisko, Lexell & Soderberg, 2007b). Links can be made with Siegrist & Währendorf’s (2009) pan-European study, which found for people in early old age being carers (in general, not necessarily for people with ABI), reduced opportunities for social exchange and reciprocity was a predictor of reduced quality of life.

Mitigating factors against caregiver strain do emerging from the research. Indeed, caregiver support is important for significant others of those with ABI (Manskow et al., 2015) in the form of information and preparation and training for the caregiving role (Cecil et al., 2010), especially when public services reduce or withdraw and they are left in sole charge of their loved one (Mazaux & Richer, 1998). The implications are that caregiver burden can be predicted with low levels of the care recipient’s functional status and a lack of social network (Manskow et al., 2015). Social capital in the form of family and friends can be especially important. Similarly, involvement in the community and, for example, church activities (Wells, Dywan & Dumas, 2005), linking back to Bourdieu (1990).

Of course significant others who are caregivers may hold differing roles and relationships with the person with the ABI, which leads to consideration as to
whether some roles and relationships are impacted greater than others. It is proposed that parents who are caregivers may experience greater satisfaction in their role than caregiver spouses, who in turn may experience greater satisfaction than adult offspring as caregivers (Savage & Bailey, 2004). However these findings come from a review that is now somewhat dated.

Emotional issues may arise when a parent becomes a caregiver for an adult son or daughter with an ABI, due to needing to renegotiate family dynamics: concerns may arise over issues of dependence and independence and the individual with ABI may perceive that they are being treated as a child once more (Jones & Morris, 2012). One study compared distress and family functioning in spouses, with distress in parents, of individuals with ABI (Anderson et al., 2009). Physical and communication impairments of the individual with the ABI were not predictors of distress, as opposed to behavioural and cognitive impairments, which were. The impact on family functioning appeared to be less for parent caregivers than spouse caregivers. This could be explained by an interruption of family dyad e.g. the marriage partnership, by way of spouse caregivers having a significant impact on the family functioning as a whole, which is not affected in the same way with the parent caregivers (Anderson et al., 2009). Furthermore, cultural variations in the understanding of ABI may be apparent and impact on caregiving. Issues may arise such as different boundaries around talking to rehabilitation staff about feelings and cultural perceptions about any injury to the brain being associated with madness (Simpson, Mohr & Redman, 2000).

4.6.2 Rewards in the role of giving care to people with ABI

There has been criticism that research into caregiving has seen a bias towards identifying the negative aspects with positive aspects largely ignored (Folkman & Moskovitz, 2000). It may be that a bias exists in the literature on this negative aspect, due to the research being predominantly with caregivers’ experiences in situations of severe ABI (Machamer, Temkin & Dikmen, 2002). The positive aspects of being in a caregiving role may mitigate against the negative psychological issues and giving care can be a source of satisfaction (de Arroyabe, Alve, Las Hayas & Zubizarreta, 2013; Las Hayas, de Arroyabe & Calvete, 2014). More caregivers have been found to be satisfied with their role than dissatisfied (Perlesz, Kinsella & Crowe, 2000; Machamer, Temkin & Dikman, 2002; Wells, Dywan & Dumas, 2005). A co-occurrence of the positive and negative issues may be apparent in any one
day (Folkman & Moskovitz, 2000), suggesting a cognitive dissonance (Festinger, 1957). Family relationships can develop post-injury, bringing family members closer together (Nichols & Kosciulek, 2014). Development in the spiritual aspect of life may occur, due to a re-evaluation of priorities and values following serious injury such as ABI (Conneeley, 2002). One impact of having a family member with an ABI may be, in some cases, that family relationships are strengthened, due to more appreciation of each other (Conneeley, 2012).

4.6.3 Occupational disruption in the role of giving care to people with ABI

It should be borne in mind that many occupations and roles within relationships, such as families and marital partnerships are co-constructed and when occupations and roles are disrupted for one member in the relationship it impacts on others. Similarly, the experience of participating in occupations is co-created within such relationships, with interests merging and the way in which engagement takes place being adapted together (Bonsall, 2014a; Bonsall, 2014b). Occupational disruption has been researched from the perspective of roles of caregivers outside of the field of ABI. Professional lives or main occupations have been found to be affected, either in the form of re-organisation or needing to forsake a fulfilling work role, in order to preserve family life (Lefebvre, Cloutier & Levert, 2008). One study proposed that still being able to engage in the hobbyist role for caregivers mitigated against levels of sorrow, which were high following diagnosis and longer term (Lee et al., 2001). Another study focussing on roles of caregivers to older people brought up the issue of role loss, where a marital partner may feel in limbo now that the relationship is changed and can no longer conceptualise it within the conventional married / divorced / widowed description of status impacting on role definition (Hasselkus, 1998). Parallels may potentially be able to draw from these studies and the situation of ABI.

Occupational disruption has been identified for some taking on the role of caregiver to individuals with ABI. This may stem from a breakdown in social circles when a family member has an ABI and time is taken away for the occupation of caregiving itself, impacting on previous routines that involve leisure and paid occupation (Martin, 2012). Social networks are seen to be important to caregivers of people with ABI, in terms of access to information and being able to have respite from the caregiving role (Blake, 2008). Continued giving of care may result in fatigue,
impacting on motivation to continue with former occupations or experience new ones; a restricted occupational world results (Rudman, Hebert & Reid, 2005). Where social opportunities and networks become limited for the person with ABI it has a tendency to spill over to the caregiver, suggesting restrictions on the occupational world of the caregiver similar to the individual with the ABI. This may be due to caregivers feeling unable to spend extended periods of time away from the caregiver role or because the occupation was something that they previously did together and is now restricted (Laliberte-Rudman, Hebert & Reid, 2006).

With respect to gender, females who give care to relatives with one form of ABI, namely stroke, have been found to have more difficulty in completing tasks than male caregivers in similar situations. An explanation for this may be due to the additional caregiver role being on top of competing family obligations for females or males taking a differing approach to problem solving (Jessup, Bakas, McLennon & Weaver, 2015), though such explanations are only suggestions. Additional research on the occupational impact of caregiving is called for, to help understand the impact of occupational balance and the meaning caregivers ascribe to holding the role (Su Lin Yong & Price, 2014). No current research is available on occupational identity and significant others in the situation of ABI.

### 4.7 Narrative disruption

Having explored how the issues of occupational disruption and occupational identity may impact on an individual with ABI or their significant other, attention now turns to the issue of the disrupted narrative. In Chapter 3 it was proposed that the meaning-making in the engagement of occupations is expressed through narrative, thus disruption to occupational engagement will have a detrimental impact on the narrative.

#### 4.7.1 Narrative disruption for people with illness or acquired disability

In his seminal work, *The Wounded Storyteller*, Arthur Frank’s emphasises that when people become ill their personal stories become told through a body that is now wounded: this is a body with which they are not familiar (Frank, 1995). The bodily experience affects the processes of thinking and memory and subsequently is influential in the way language is drawn on in the narrative (Hydén, 2013). The individual is usually cared for by a range of health professionals, who engage in a generalised medical view about the disease, viewing them as a *patient* and
dissociating body symptoms from the person with individual needs and experience of suffering. However this is not the voice of the individual who has lost their familiar internalised life map and destination (the former life map now being of little use) (Frank, 1995).

The form of the narrative draws on the cultural stock of stories from which to make meaning (Widdershoven, 1993). Thus if socially constructed stories of illness and disability traditionally portray negative images, the newly acquired narrative may become infused with these. Chapter 3 discussed how the canonical story structures become the template on which to base life narratives, which likewise typically encounter difficulties, as in the case of illness and disability (McAdams, 1993; Bruner, 1999; Cashdan, 1999). However, the canonical story structure ends in conquest and celebration (McAdams, 1993; Cashdan, 1999) yet with acquired illness or disability it may be some time before this is apparent, if ever.

The coherent story can become lost (Bruner, 1990). The reflexive processes in narrative lead to a psychic reorganisation in the mind (Giddens, 1991), thus the inner story will require significant revision before this is satisfied. This will impact on the narrative identity, which although is always dynamic and changing over time (Ricoeur, 1991), it will not have anticipated such major revisions needing to be made so quickly. Polkinghorne (1998) talks of potential unhappiness or despair if an incomplete or confused identity remains.

A number of strategies may assist in healing the disrupted narrative. Autobiographies have been described by Giddens as having the power to correct the past, offering comfort and support to the past self and then projecting a new image of self for the future. Holding a conversation with the self about stressful events can help in coming to terms with likely implications (Giddens, 1991; Mattingly, 1998). Expressing narratives may offer the opportunity for a narrator to offer a different identity than that assumed of them, especially with illness narratives where it may be an assumption that the individual is wounded by their experience: the individual may actually carry a positive identity due to the illness experience, more akin to the warrior than the wounded (Jones & Bunton, 2004). This relates to Frank’s narrative genres, as previously mentioned in Chapter 3, where different categorisations of narrative are proposed: the restitution narrative; the chaos narrative and the quest narrative (Frank, 1995).
4.7.2 Narrative disruption and ABI

The issues of being a wounded storyteller may indeed be apparent for those with an ABI. Furthermore, some individuals with specific memory deficits, for example following focal brain damage, lose the ability to self-narrate and experience *dysnarratavia*. There may be a lack of being able to draw on memories of past experience of all manner of things, including work and relationships. A lack of agreement exists around whether this leads to a loss of sense of identity. Andrews suggests that it does, by way of memory being key to identity (Andrews, 2014). If this were the case it would suggest a relationship between *the self* and memory and that loss of memory leads to loss of self, which is a complex and much debated concept (Eakin, 1999). Frank argues that the ability to narrate is essential for the human being to be able to be social and to flourish (Frank, 2010), thus suggesting that dysnarratavia can limit social functioning and flourishing.

Of course not all people with ABI will have specific memory deficits. However, the cultural stock of stories around ABI can form the basis of negative stereotyping, often framed within paternalistic rehabilitation approaches (Weatherhead & Todd, 2014). The new found existence can lead to one of uncertainty around future possibilities, for example around being able to have successful relationships or maintain a career, due to acquired impairments. Thus imagined futures will be in a state of flux and interrupt the narrative in terms of autobiographical time being perceived in past, present and future (Ochs & Capps, 1996).

One must be mindful that the ABI is not a singular event but remains a backdrop to life moving forward (Flynn, Daiches & Weatherhead, 2014). New meaning-making is required of the actively unfolding plot, now that the present perspective is new and different (Josselson, 2004; Schiff, 2012). There is the potential to access the psychological processes and social reality that is taking place in this changed perspective through the narrative (Gergen, 1994; Schiff, 2012).

4.7.3 Narrative disruption and impact on identity with ABI

Consideration now leads to connecting the disrupted narrative after ABI to any potential impact on identity. Early research considering the narrative post-ABI suggests positive or neutral self-image. Two strategies might be utilised in the narrative mode of cognition: *dissociating* the self from the ABI, or seeing worthiness in the self *because of* the ABI, providing an opportunity to uncover a life goal. A
number of narrative genres are suggested: the self better than others by way of making comparisons with more tragic scenarios; the recovering self by way of seeing the self on a pathway to recovery; the protesting self who viewed the social environment as oppressive; and the self living in the here and now, omitting comparisons with experiences of the past and possible selves (Nochi, 2000). These narrative forms differ from Frank’s quest, restoration or chaos narratives, possibly due to the specificity of ABI, but it must be taken into consideration that this is not an extensive study. Other narrative forms from individuals with ABI suggest the common occurrence of striving statements, for example reflecting goals about what they would like to be able to do in the future (Douglas, 2013).

It has been suggested that purely negative representations of identity post-ABI are crude representations and that several identities can co-exist. The dominant western cultural form of the individual being independent, autonomous and stable may have influenced this idea of there being a lost self post-ABI (Gelech & Desjardins, 2010). Narratives of individuals post-ABI, tended to have both a public identity of loss and a private identity of continuity of self, essentially feeling like the same person. The grief and loss suggested by other studies was transformed for some into moral growth, including compassion and respect for life (Gelech & Desjardins, 2010).

Considering that the identity realigns post-ABI, it does not do so in a linear fashion, over time. It is proposed that identity redevelopment in the narrative post-ABI is both protracted and cyclical, with tentative resolutions but continuing well past functional recovery. The cycle revolves around the identity being at times contracted (not being able to be the person they were or do the things they previously did) and other times expanded (feeling reborn with a second chance at life following severe trauma) (Muenchberger, Kendall & Neal, 2008). The opportunity to explore the re-construction of the narrative post-ABI is recommended for rehabilitation (Heller, Mukherjee, Levin & Reis, 2006). Even when ABI rehabilitation works specifically towards a resolution of identity issues it is only successful for some: a pre-morbid personality type to be able to examine life is required (Ben-Yishay, 2008).

4.7.4 Narrative disruption and the significant other

Consideration needs to be given to the narratives constructed by significant others, such as family members and rehabilitation staff and how this impacts on the narrative of the individual with an ABI. It may be that negative images contained
within the discourse of such significant others, referring to loss and deficit, compound the loss of self within the narrative. This can be complicated by some individuals with ABI being reliant on significant others to recount past histories (Cloute, Mitchell & Yates, 2008).

Because the family environment is essentially a social one, the person who experiences an ABI will not be alone in feeling the impact on their narrative. Significant others in shared relationships will be affected, not only by differences in family functioning practicalities but the similar issues of disruption to the narrative with respect to the present and imagined futures. Little, if any published research evidence is available on narrative disruption for significant others of people with ABI.

However, an interpretation of the situation may be that the significant other is trying to make sense of both their own narrative and that of the person with the ABI to which they are connected. The same idea about post-ABI identity needing to be renegotiated exists for significant others as well as the individual with ABI, with cycles of reforming and stability in the identity. A loss of self in the identity for the significant other can co-occur with loss of identity related to the relationship (Godwin, Chappell & Kreutzer, 2014). In situations of ABI, where communication and cognitive impairments are common, it may be that the individual with the ABI can no longer construct or communicate a narrative and relies on a significant other to do this for them. For example, amnesia may produce an arrested narration, where a story fails to form, or a frontal lobe lesion may produce an uncontrolled narration due to confabulation. What must be borne in mind is that the story told by the significant other will always differ from that of the person with the ABI, even if recounting the same event, as they will both own differing experiences: the authorial voice can become lost or silenced and the vicarious authorial voice comes from the significant other instead (Hydēn, 2008).

Attention turns to how the significant other might begin to locate their loved one's story in everyday life. One way in which the significant other might engage with trying to understand their loved one is through reading stories of the experience of others with ABI. This enables the significant other to locate the experience of their loved one and try to understand what they may be experiencing. Symptoms and treatments might be compared this way. In addition this may serve to legitimise certain anti-social or unusual behaviours that are apparent, to be able to attribute
them to the ABI itself as opposed to the person and enable a way to broker discussing them together (Easton & Atkin, 2014).

There may be a dilemma expressed in the narrative with respect to mis-alignment with normative discourses for significant others caring for people with ABI, i.e. dominant ideas in society about how people should fulfil their roles (Walther, Redstone & Holmgren 2014). For example, they may hold expectations about being a caring enough carer or a good enough wife, that can result in conflicting viewpoints on how to behave in some situations e.g. letting a husband with an ABI drink alcohol in a social situation, knowing that it may lead to him expressing anti-social behaviour causing conflict between the wife and carer role. Therapeutic intervention can take the approach of helping to shape alternative discourses within which to live by (Walther, Redstone & Holmgren 2014). Children, where a parent acquires a brain injury, have been found to hold narrative accounts likened to myths and misconceptions about brain injury and express ideas about family life having stopped (Daisley, Prangnell & Seed, 2014). These ideas link back to ideas discussed in Chapter 3, about folklore and fairy tales being incorporated into narrative form (McAdams, 1993; Cashdan, 1999).

4.8 Research aims
To explore the narrated experience of daily life and engagement in occupations, of people living in the social context of a rural location, post ABI.

To explore this narrated experience for both those with ABI and significant others affected through their social relationship to a person with ABI.

4.9 Research purpose
To investigate:
(i) What the telling of the narrative reveals about how people construct new occupational relationships with their post-ABI worlds.
(ii) How engagement in occupations and roles is constructed in the narrative.
(iii) If and how the social context of a rural location has an influence on the post-ABI experience.
4.10 Chapter summary

The chapter highlights the disruptive influence of ABI on occupation, identity and the narrative and emphasises the inter-dependent relationship between occupation, identity and narrative: engaging in occupations is limited; the identity is compromised; and the meaning of this may be accessed through listening to the disrupted narrative of those with ABI or significant others. This is the complicating factor to the plot of this thesis presented as a three-act story. A biomedical or some biopsychosocial approaches to re-engagement in occupation would consider the physical and cognitive impairments of the individual and look towards social / community re-integration and re-training around the impaired areas. However, if the inter-relationship between occupation, identity and narrative is considered in more depth, a narrative approach to rehabilitation may have the potential to impact on occupation and identity.
Chapter 5  
Narrative as Methodology

5.1 Introduction to the chapter

“When you’re ly, when you had to lie flat with one pillow so you can’t really do anything, so I just used to lie there listening and I’ve done it as meself as a nurse, used to talk about the varicose veins in the corner or the hernia over there. And I became the subarach in the corner. That’s who I was. And then when I came back after the angiogram I was a failed embolisation. And I kept thinking, “I do have a name.” But then I thought, ‘I’ve done it meself, on a ward.’”

This quote reflects the way in which participant Susan uses the narrative to demonstrate how she socially constructed ways of conceptualising patients on the ward where she worked, only to find nurses producing similar social constructions of her when she became a patient. Susan experienced a sub-arachnoid haemorrhage in her forties whilst on duty as a nurse. Her experience of fatigue and a second neurological condition led to her taking early retirement. She told her life story some eight years after experiencing the ABI.

This chapter considers how constructivist approaches were adopted by this research, with respect to the methodology. Careful consideration to the approaches adopted by this particular research is offered and as such both contextualises and justifies it as being theoretically derived with coherence from a research perspective. This demonstrates how the approach can feasibly lead to a legitimate contribution to the field of study. The chapter spells out the research paradigm adopted within this study, which is post-positivist and constructionist. It further serves to reveal the underpinning values that guided the actions carried out for both data gathering and analysis, by way of a continuing development of the plot behind the thesis as a story.

5.2 Ontological and epistemological positions

Attention first turns to assumptions about the nature of reality behind research. The conventional objectivist position is one of the world having a ‘single tangible reality’ and inquiry can ultimately lead to a predictable and controlled understanding of it. In contrast, the understanding adopted by this research is one of the world having ‘multiple constructed realities’ and inquiry leads to uncovering complexity, unlikely to predict and control: an understanding can be revealed to some degree. It adopts a relativist position as opposed to a realist position (Guba & Lincoln, 1989, p37).
The stance predominantly taken by biomedical practitioners working with people whose lives are affected by ABI is dominated by biomedical research, aligned with a realist perspective. Despite the most recent UK national clinical guidelines acknowledging that randomised controlled trials (RCT) present a challenge in the field of ABI, due to its heterogeneity, they still draw from predominantly biomedical literature utilising a discourse around clinical circumstances and science (BSRM & RCP, 2003). The biomedical or biopsychosocial reality is important for the treatment of biomedical symptoms that follow natural laws, such as life saving interventions, cognitive impairment and practice of functional skills in ABI, and such research therefore has a place. However, this research does not adopt this stance. It would appear that this research adopts an opposing ontological position to research commonly undertaken in the field of ABI (Crotty, 1998). Indeed, it proposes additional or alternative realities that may co-exist and an explanation of this is now considered.

This research is concerned with ABI, but not with aspects of ABI that follows natural laws of biomedicine. It is interested in how people construct new occupational relationships with their post-ABI worlds. It is interested in how engagement in occupations and roles is constructed in the narrative and if and how the rural location has an influence on the post-ABI experience. Thus, this research adopts a constructionist position, whereby the personal meanings derived from accounts of the participants are utilised to represent their constructed reality of the world. It is described as a relativist ontology (Lincoln & Guba, 1985). It allows commonly taken-for-granted understandings of phenomena to be viewed from a different perspective and construct alternative understandings (Ballinger, 2004). It distances itself from the perspective of a single reality (realist) or truth and objectivist position (Crotty, 1998). The constructionist stance accepts that all perspectives, whether they be positivist scientific or non-scientific are merely constructions and none produce an objective reality, but each can provide a legitimate contribution to understanding (Crotty, 1998). This research aims to offer such alternative constructions, for people whose lives are affected by ABI.

It has been suggested that the objectivist position and the search for a single truth has lost its dominance to constructivism in more recent times (Crotty, 1998). Whilst this may carry some credence in the social sciences from which Crotty hails, it is certainly not the situation in UK healthcare research, where evidence-based practice still prioritises the likes of the RCT over the qualitative research interview with its
results that cannot be generalisable. This is possibly due to needing to be able to show value for money in a National Health Service (NHS) with its need to have information quickly to underpin improvement (Blair & Robertson, 2005). Although the researcher here is a registered health professional she is not investigating the phenomena from within the domains of the NHS, which affords a degree of licence to undertake research differently and innovatively. Furthermore, many people living with ABI have little or no further access to specialist health services and the research is focused on their post-rehabilitation health and wellbeing. The research is therefore more aligned to Crotty’s social science background and constructivist research (Crotty, 1998).

5.3 Positionality

Attention now turns to the subjective position of the individual researcher of this research and what considerations are there with respect to any truth claims. Individuals are constructing personal meaning to the experience of living with ABI, as they engage with daily life. Their experience is subjective and not objective. Of course a whole series of individual subjective experiences would hold limited value as such, so the constructivist researcher needs to be seeking to join subjective experiences by way of teasing out similarities and overlaps (Guba & Lincoln, 1989). Constructivist research does not seek to make truth claims as such: the truth sought by objectivist epistemology is replaced here with constructing the most sophisticated, informed and competent presentation of a phenomenon. Potentially more sophisticated constructions will become apparent with further research, at some point in the future and replace this one (Guba & Lincoln, 1989).

If this research adopted an objectivist position there would be an assumption that researcher and phenomenon under study would be detached and quite separate. However in this research it assumed that the researcher and the phenomenon, or research participant, were inter-connected and exerted influence on each other: the emerging data has been created from the interaction of the two individuals (Guba & Lincoln, 1989). For example, how the researcher responded to the discourse of the participant in the research interview may have influenced how and what further issues the participant proceeded to disclose. As each research text is always produced from an authority position of a researcher, in constructivist research like this research, there needs to be a declaration of researcher position, in order to
deconstruct or demystify the findings (Erickson, 2013). Indeed any interpretations will have been ‘filtered through the lenses of language, gender, social class, race and ethnicity’ (Denzin & Lincoln, 2013b, p.24). Furthermore, research does not take place without external influence, such as the reasons for undertaking the research and each researcher will embark on research with a particular standpoint (Clough & Nutbrown, 2012). For example biomedical research aligned to medicine, is positioned with evidence-based practice in mind i.e. a search for proof of what works and considered by some as claiming absolute authority (Blair & Robertson, 2005). The position here is far from that one, being constructionist.

A declaration enhances the transparency of any interpretation, by way of offering clarity to the background and interests of the researcher, potentially reducing bias afforded by particular values or power positions. In this way the researcher was considered an active presence within the study (Erikson, 2013). So what kind of account of positionality is offered here by the researcher of this study?:

I am a white, British, female qualitative researcher and occupational therapist, working as an educator within a university, with an interest in acquired brain injury. My involvement with people affected by ABI is through being a trustee of a neurological charity where a number of fellow trustees have neurological conditions, including ABI. In my teaching, I work with service users to facilitate the telling of their life story in the classroom, so students will have a defined learning space to hear service user narratives of individual experience, hopefully incorporating this into their future practice as occupational therapists. I value the empowerment of service users and respect their personal experience as knowledge to be shared.

I am not engaged in rehabilitation practice, though still hold professional registration as an occupational therapist. Therefore I am not protective of current occupational therapy rehabilitation practice in this field, being removed from it, but I respect the expertise of therapists in this field. I certainly do value the Profession and recognise the impact of occupation on people’s lives. Therefore, my enquiry is not value-free but offers a degree of removal from the rehabilitation field. I hold a masters degree in rehabilitation management therefore have an interest in researching alternative and creative ways of managing rehabilitation. I have lived in a rural area for almost 30 years, though it is well served by services and urban areas.

By offering this researcher’s position it might go some way to address issues of criticality and reveal some of the values at work in the research produced here (Clough & Nutbrown, 2012). In summary, the position adopted by this research has a relativist ontology and a constructionist epistemology. Any theoretical perspectives will have goodness of fit with this standpoint.
5.4 Theoretical perspectives

As previously declared, this study is concerned with people whose lives have been affected by ABI and any issues particular to living within rural areas. In terms of the health and social care services that statute identifies for this service user group, provision is focused within physical medicine, due to many people who sustain a brain injury requiring medical intervention, sometimes in order to preserve life initially. Health care services that follow on from acute medical intervention tend to be rehabilitation services, based on either a biomedical or biospsychosocial approach, utilising an evidence-based practice approach to intervention. Within the physical rehabilitation setting the gold standard for evidence-based practice has long been considered to be the RCT, requiring a strictly controlled environment in which rehabilitation outcomes are delivered, to similar subjects (Kersten, Ellis-Hill, McPherson & Harrington, 2010): an objectivist position. However, ABI comes in many guises with widely varying after-effects on daily living issues for rehabilitation. So perhaps once the biomedical issues of ABI are stabilised the placement service provision within the physical medicine becomes of less good fit. Furthermore some members of the rehabilitation team (occupational therapists) have a domain of concern that is removed from biomedical intervention, such as occupational engagement.

Consideration now turns to how this is being borne out in the development of services for people with ABI and if there is better alignment proposed between needs and service provision with respect to occupational therapy, where occupation is of prime concern. The College of Occupational Therapists’ (COT) guidance for members of the Profession working with people with ABI is still aligned to the biomedical and biospsychosocial approaches, being mapped against the national clinical guidelines produced by physicians and rehabilitation medicine and promotes outcomes-based practice to demonstrate effectiveness of intervention (COT, 2013). The consequence is, in so far as psychological issues are concerned, that this robust and credible guidance document from the Profession only directs occupational therapists to consider mental capacity and cognitive issues, with no mention of other psychological issues such as identity and mental health which occurs in the ABI literature discussed in preceding chapters of this thesis. This is unfortunate, as the Profession’s Standards of Proficiency for the UK require registered occupational therapists to also meet psychological occupational needs of
service users (HCPC, 2013). From this it would be expected that a breadth of psychological occupational needs would be considered. Furthermore, criticism is levied at the tendency for occupational therapy research to focus on activities that can be divided into such as self-care and any cognitive issues impacting it, and that it has diverted attention away from the important focus of meaningful occupations and stayed aligned to purposeful occupations (Hammell, 2004).

This separation of the occupational issues (physical, psychological and social) for people with ABI may have come about as follows. The divergence of occupational therapists working in one or the other fields of physical health or mental health might be explained by the established separate commissioning of physical and mental health services in the UK, resulting in systemic failures over recent years (Smyth, 2016). One consequence, in the field of ABI, is that occupational therapists tend to be employed in physical health settings, often within teams headed by the rehabilitation medical consultant who places high value on research underpinned by the objectivist epistemology. It is not surprising therefore that constructivist or interpretivist research is limited in this field to date. However, it has been argued that interpretivist research may offer additional insights into why some responses to treatment occur, as opposed to a focus on the dominance of the RCT in this physical setting (Kersten, Ellis-Hill, McPherson & Harrington, 2010). Indeed this research was interested in the rich descriptions of the social world of people affected by ABI, their occupational world. It had a focus on how the relationship of occupation, identity and narrative exists in a triad for people whose lives are affected by ABI. Quantitative research arising out of the positivist tradition has little regard for such detail, as it could cloud any generalisations that could be made from the research data (Denzin & Lincoln, 2013b). Indeed calls from within the Profession itself encourages generating knowledge specific to the Profession, as opposed to following biomedicine. Interpretive theory has been cited as a basis (Blair & Robertson, 2005). Interpretivist research is arguably more appropriate.

Occupational therapists practicing in UK rehabilitation settings appear to overlook suggestions coming from research that crosses this physical / psychological divide: the research advocates that people with ABI have a need to explore identity issues, to enable effective moving forward in rehabilitation. The current rehabilitation practice of retraining in a biopsychosocial context does not appear to realise high rates of successful social integration and occupation continues to be disrupted. Identity issues are often unresolved and strands of the former self left
unacknowledged within the present self. Therefore there is a case for trying to influence this gap in theory and practice.

**Figure 1: The relationship between occupation, narrative and identity**

![Diagram showing the relationship between occupation, narrative, and identity]

The research approach adopted must have goodness of fit with the domain of concern here and theoretical perspective underpinning this research i.e. occupation, identity and narrative and the implications for occupational therapy. Consequentially, an occupational perspective is sought in this research, as opposed to one of objective biomedical impairment, which is measured and evaluated accordingly. It is with this premise in mind that this research seeks to approach issues for people affected by ABI not from a biomedical perspective, but by revisiting the Profession’s philosophical roots and taking an occupational approach. The assignment of occupational therapists to biomedical teams is purely due to service delivery patterns as opposed to being true to the Profession’s theoretical underpinning. This would lead to an assumption that the positivist or hard science stance, often associated with occupational therapy intervention and ABI has come about due to service developments in the UK over the past decades, as opposed to staying aligned to occupational needs and the Profession’s roots.

However, the ideas behind this research evolved as the study progressed as opposed to being clear from the outset. Originally ideas behind this research reflected the background of the researcher as an occupational therapist who had engaged with the published research on ABI, stemming from a biopsychosocial approach and the original research questions reflected this. Research into barriers
to engagement in daily occupations for people affected by ABI living in rural communities was the focus. However, this was revised to focus more on how participants narrated their occupational lives, as the research progressed, reflecting the links between occupation, narrative and identity. Thus the biomedical / biopsychosocial perspective is put aside in this research, in favour of alternative post-positivist approaches. This research offers an alternative perspective that may lead to creative suggestions about possible ways for occupational therapists to work with people affected by ABI in the future, different to established protocols from the biopsychosocial approach of practice.

Furthermore, the occupational perspective is one compatible with the research discipline of occupational science. This approach argues that whilst medicine and its positivist stance is concerned with preserving life, an occupational perspective is concerned with the quality of the life preserved, the people living in individualised contexts facing environmental challenges to engage in occupations. A study that decontextualises the individual from their environment is thus inappropriate (Yerxa et al., 1990). Plus, the positivist stance operates within a position of privilege to measure and study an individual against a single truth or reality, as opposed to this research, where a constructionist stance of multiple realities, empowers the research participant to offer their own standpoint on the world. Empowerment was a significant issue for this researcher, who purported to operate from a person-centred approach with respect and close attention paid to the explicit message from the participants.

Discussion is warranted about the implications around the study being reproducible. This relativist ontological position suggested above works well with an interpretivist theoretical perspective, where the researcher and participant of research interact and shape one another in a naturalistic setting (Denzin & Lincoln, 2013b) i.e. the researcher and person affected by ABI interact in a typical setting for the individual affected by the ABI: phenomena researched were influenced by the experiences and background of both parties. This is very different to working from a realist positivist position, where any researcher should be able to produce the same results under the same conditions. However, the complexity and heterogeneity of living with ABI in individual contexts was under consideration in this study, as well as the rich description of the experiences of those affected by ABI, hence a reproducible study is not applicable.
The complexity and heterogeneity in people’s lives is of relevance here. The individual way of perceiving and ascribing meaning to the world comes through development from birth within a complex cultural system, which each individual responds to and interacts with. This ‘continuing socially determined interference’ serves to construct the person that each becomes. He / she establishes habits within the institutions of life around them, so much so that their taken-for-granted world, use of language and metaphor, becomes a socially constructed reality, far beyond what he / she is conscious of (Berger & Luckmann, 1966, p72). There is an acceptance in this research that the world of the participant is subjective and individual, and that reality for the participants is impossible to know except from within their own mind: they apply their own perceptions and meaning to reality. As a result what was taken into account from this standpoint was an acceptance that words and discourse in the research would have different meaning to individuals, dependent on such as cultural background and the domain of concern within the interview (Dyson & Brown, 2006). For example within this research the participant may have assumed that the researcher was only interested in their ABI experience, having been recruited from a pool of people whose lives are affected by ABI. Thus making it clear from the outset that their whole narrated life was of interest was important, in order to avoid such ambiguity as far as possible.

5.5 Narrative methodology

5.5.1 Narratives within research

Adopting this interpretive theoretical perspective and its underpinning premise of reality being socially constructed, leads this research to ethnomethodology. The research concerned uncovering how participants, in this case people whose lives were affected by ABI, construct meaning and social order in their life. The researcher suspended taken-for-granted social realities, such as the construct of disability, in order to uncover how the participant constructed such concepts in their reality (Holstein & Gubrium, 2013). The researcher approached this research from the following viewpoint: if the reality of life affected by ABI is constructed by the participants, how do they accomplish this, within the given situation of the research interview? It was accepted that participants in alternative circumstances to these research interviews might offer variations in conversational accounts: this did not reduce the credibility of the accounts, it is merely illustrative of a symbolic interaction
with this particular researcher, under the context of this research (Dyson & Brown, 2006).

In order to keep methodological coherence within this research, it would not serve well to draw on approaches that were heavily interventionist on behalf of the researcher. The approach needed to be able to uncover, and allow emergence of, perception and meaning associated with the participant’s worldview of living with ABI in a rural setting. So how was this achieved? Strategies were selected that were as non-directive as possible within lightly structured interview situations, aligned with ethnomethodology (Crotty, 1998). For this purpose a life story or narrative interview approach was adopted. This was indeed pertinent, since the research has already made claim to the triadic relationship between occupation, identity and narrative.

Narrative is underpinned by philosophical assumptions about the realm of meaning in human existence and the premise that human experience is made meaningful through narratives (Polkinghorne, 1988). Personal reality is constructed through the narrative (Gergen, 1994). The human organism exists in the material, organic and mental realm (matter, life and consciousness). The mental realm seeks to understand the whole being and make meaning. It is constantly active in trying to make connections and relationships between things and describes this as narrative meaning. People often have little awareness of how this internal meaning is revealed to the world as it is done unconsciously through our actions and speech (Polkinghorne, 1988). Thus an individual’s psychological processes and social reality could potentially be accessed through their narrative (Schiff, 2012). It is these internal meanings and an understanding of the psychological processes in the narrated lives of people affected by ABI that were of interest here.

So how does this contrast with positivism and biomedical research? Narrative approaches function outside of the traditional positivist perspective of the way in which reality is constructed. When life is understood from an objective positivist viewpoint it is in terms of things being invariant and stable, obeying scientific laws and being independent of context. In contrast, a narrative human science viewpoint rests upon the idea that human beings create ‘products of the mind’ that are experienced as real, influenced by the cultural milieu (Bruner, 1986, p45). This fits with constructionist and interpretivist subjective principles. Traditional positivist approaches of exploring neuroscience (such as ABI issues) are polar opposite to narrative approaches. The traditional approach predominates in neuroscience
research, from a biomedical-led perspective, possibly due to a suspended belief from the biomedical field that someone who expresses a misperception of functional deficits (as is often the case with ABI) can contribute meaningfully to the research base (Weatherhead & Todd, 2014). However in this research those contributions were valid and important.

But the objective and subjective can be complimentary. It has been suggested that the objective and subjective should be embraced for greater benefit rather than scientific objectivity viewing human subjectivity as its polar opposite and a potential challenge (Hurwitz, Geenhalgh and Skultans, 2004). It could be argued that narrative is indeed objective in itself. The narrative provides a perspective on related events. In terms of the individual person, the narration is true to that individual’s circumstance and emotion, specific and individual. The scientific discourse seeks to reject perspective, but in doing so it may be moving away from objectivity itself (Goldie, 2004). The narrative is merely another construction of reality, alongside the objective scientific one.

Recent years have seen a growing interest in the use of narratives in research. This surge has led to it being problematic in defining what is narrative research and what is not (Schiff, 2012). This develops Mishler’s concern that there is a state of anarchy over what constitutes narrative and little consensus on the purposes of telling stories and why are they told. He advocates acknowledgement of a widespread approach to research using narratives and with it diversity in proceeding with analysis (Mishler, 1995). Deciding where to place narrative within a defined methodology such as ethnography, phenomenology or hermeneutics is not easy to the extent that it is suggested:

‘narrative research eschews methodological orthodoxy in favor of doing what is necessary to capture the lived experience of people in terms of their own meaning making and to theorize about it in insightful ways.’

Josselson, 2011, p225.

Therefore this research does not seek to claim a defined space in ethnography, phenomenology or hermeneutics.

There are two main historical beginnings of the narrative movement: person-centred case studies of western sociology and psychology; and approaches within the humanities such as structuralist, post-modern, psychoanalytic and deconstructionist
This research is case study narrative and does not draw on such as psychoanalysis or a Foucaudian approach and is more akin to the former suggestion. Narrative research has been loosely divided into *event-centred* and *experience-centred*, depending on the domain of concern of the research topic (Andrews, Squire & Tamboukou, 2013). Although all participants in this research would have been eligible to narrate the event of injury in a research interview, this was not the focus. The experience of living a life affected by ABI in a rural setting was the domain of concern here: some participants chose to narrate the event as part of the interview but it was not a requirement.

A minimalist intervention version of the narrative approach would have goodness of fit with the research paradigm proposed thus far in the research. Wengraf’s approach to gathering the narrative data is a minimalist interviewer intervention (Wengraf, 2001). It is derived from the biographical-interpretive method of German sociologists interviewing holocaust survivors and Nazi soldiers and suggests that accounts elicited from open-ended questions can reveal unconscious defences (Holloway & Jefferson, 2013). Wengraf advocates the adoption of a single question followed by minimal intervention or interaction (Wengraf, 2001). Theoretically this approach serves to minimise the ‘socio’ in Frank’s socio-narratology i.e. any influence from the dialogic nature of the researcher: even being present might influence the course of the data gathered and the content (Frank, 2010). Wengraf’s approach attempts to reduce this interactive element between participant and researcher and he promotes the application of the single question inducing narrative (SQUIN). This was therefore adopted.

Chapter 4 has already laid claim to a number of points about people’s narrated lives, which are raised again here, to demonstrate the coherence between research topic and research paradigm: discourse is key to expression in the narrative, with it revealing meaningfulness in people’s lives (Polkinghorne, 1988); the impact of culture on the discourse and the resulting symbolism performed within the narrative is significant (Mattingly, 1998); and psychological processes are responding to the narrative heard (Bruner, 1990). Thus the methodology of this research, with people whose lives are affected by ABI, looked to place importance on the discourse, incorporate it into the analysis stage, along with symbolic interaction and psychological perspectives.
5.5.2 Case study research

Interviewing participants in depth to uncover personal narratives typically produces case study research. A case study possesses the characteristics of representing human activity within the confines of the context in which it is placed, described and is temporally bound. Case studies sit outside of positivist research, like this research, being naturalistic studies of human phenomena (Gillham, 2010). The rich description provided by case study research can allow conclusions to be drawn, yet by nature of being rich and detailed, detracts from the generalisability requirements of the positivist researcher (Woodside, 2009). Unclear phenomena are offered in-depth review in case study research (Yin, 2012).

The perspective of the research here was to consider case study research two fold: firstly, the individual case study element where the individual narratives produced were considered as data in their own right; secondly, consideration of the collection of total narratives as multiple case studies, with synthesis across cases to produce cross-case findings (Yin, 2012). The individual reconstructed narratives have a defined utility: they can serve the purpose of producing an interconnectedness between those that speak them, in this case people whose lives are affected by ABI living in rural areas in this study, and those that listen to them, for example people who are looking for a greater understanding of lives affected by ABI. They can contribute to the circle of experience, allowing it to widen and reach out to those who feel alone in their personal situation (Frank, 2013). Listeners in this case may be those who are trying to make sense of the illness experience themselves: either the participant in this research or another listener who is in similar circumstances and looking to come to terms with their situation (Hydén & Brockmeier, 2008). In addition an audience may be healthcare professionals who work with people with ABI. Furthermore, cross case interpretation across the multiple cases in this research offers the potential to analyse for themes that could offer theoretical or practice-orientated insights.

5.6 Quality of the research

Quality assurance within the research study is now considered. Interpretive studies seek to explore how people construct experiences and meaning in their worlds, difficult to measure and reduce to variables (Holstein & Gubrium, 2013). The rigour
of any realist study would be seeking how the criteria of internal and external validity, reliability and objectivity had been accomplished. An interpretive study, such as this one, does not claim to meet such criteria. But can a study claim to have quality if it rejects these long-held judgments made by positivist research? Whilst the criteria above are considered acceptable criteria for positivist or realist research there are good reasons for rejecting them for measuring relativist research, like this research. Validity in positivist research is concerned with the *truth value* and generalisability of the findings. A relativist perspective, by virtue of its multiple realities does not make truth claims. Reliability looks to repeatability of a research finding, but constructivist research, like this research, is cognisant of conditions not being completely replicable another time and with changing phenomena (Guba & Lincoln, 1989). Objectivity has already been dealt with earlier.

Parallel criteria to those required for alternative positivist research lie within the bounds of *trustworthiness* (Guba & Lincoln, 1989) and in the understanding that constructionist research, like this research, seeks to demonstrate rigour through credibility, transferability, dependability and confirmability (Guba & Lincoln, 1989; Denzin & Lincoln, 2013b). Credibility is considered parallel to internal validity and in this research consideration was given to how the participants’ constructed realities would match those presented in the findings, such as member checking and prolonged engagement with participants. Historically member checking was labeled as a method of triangulation, but the term is more recently rejected with having positivist research connotations that there can actually be a check (Guba & Lincoln, 1989). Furthermore, in this research, credibility was considered by way of the epistemological consideration that the researcher had sufficient grounding in the culture of the community with which they engaged i.e. people whose lives are affected by ABI, living in rural communities, whilst at the same time recognising her limitations (Denzin & Lincoln, 2013a).

Ensuring the degree of similarity between contexts, by way of offering rich descriptions, is the means of replacing external validity with transferability of results. Having a dependability audit, by way of being open to external scrutiny and thus tracking that the research process has integrity replaces reliability in this research. Confirmability is a consideration of objectivity in the qualitative research. However, despite this research not claiming objectivity per se, the use of reflexive journal keeping goes some way to exposing potential subjective assumptions of the
The methods adopted will be discussed in Chapter 6.

5.7 Ethical considerations

Research on human subjects and asking them to engage, in this case with lengthy discussion about their personal and sometimes difficult circumstances, has an ethical duty to make a difference or produce outcomes. This may be in the form of making differences to policy, practice or professional development (Clough & Nutbrown, 2012), all potentially achievable in this research. Besides the professional development aspect of the researcher aiming to engage in postgraduate research, three additional outcomes were aspired towards, to contribute to this ethical perspective. Firstly, the researcher, being a healthcare educator in a higher education institution, she would be able to transmit knowledge gained to the healthcare professionals of the future. Secondly, service user narratives could be published to widen the circle of experience and reach out to others in similar circumstances (Frank, 2013). Finally, the opportunity to research and make suggestions for future directions in the researcher’s own Profession of occupational therapy, with interventions for people whose lives are affected by ABI, presented itself in this research.

Of course research involving people and discussion of their life story, had the potential to generate ethical dilemmas, especially pertinent where some of the participants could be considered vulnerable due to disability issues (Silverman, 2013). What is more some of the participants in this research had cognitive issues due to ABI, such as memory and concentration loss. In such circumstances care had to be taken to ensure that participants understood what the research entailed, not only in terms of being a participant during the research, but longer term in terms of generation of findings and publication. Some positivist research makes a claim for the need to introduce a degree of deception towards participants into the research to prevent contamination of variables (Guba & Lincoln, 1989). However, this research had no valid reason for requiring this (and was against the values of the researcher), so openness and clarity were requirements to avoid unnecessary exploitation. Besides, personal sense-making of participants’ life worlds and internal realities were under study in this research and thus the research would have lacked integrity if deception had been utilised (Guba & Lincoln, 1989).
Conventional safeguards such as protecting anonymity, dignity and autonomy (Guba & Lincoln, 1989) and preventing harm, fit with the principles adopted in this research. Informed consent and the right to withdraw were thus important considerations. Anonymity was considered important as the research may become a public record in the future and it was required not only to protect the anonymity of the participants but such as relatives and friends too (Holloway & Jefferson, 2013). This differs from the stronger requirement of confidentiality, whereby even anonymised data cannot be utilised in published form (Wengraf, 2001), which was not the approach utilised in this research. Exploring difficult topics was inevitable in this research so safeguards around distress needed to be considered. Procedures based on honesty, respect (Holloway & Jefferson, 2013) and empathy were implemented and will be discussed in Chapter 6.

5.8 Chapter summary

This chapter has contextualised the research in terms of being derived from relativist ontology, as opposed to a realist ontology: multiple constructed realities being present in the world, as opposed to a single truth is supported (a constructivist approach). How this research differs from traditional biomedical research in the field of ABI, by way of discussing the adopted occupational approach. A goodness of fit with a relatively non-interventionist narrative approach has been discussed, linking back to the triadic relationship of occupation, narrative and identity. Finally the quality demands of positivist research were rejected in favour of parallel requirements of trustworthiness for qualitative research and ethical considerations presented. How these principles were actually implemented in the process of the research will now be discussed in Chapter 6, by way of continued development of this thesis presented as a three-act story, in order to explore the disruption of the narrative, occupation and identity due to ABI.
Chapter 6    Method

6.1 Introduction to the chapter

E Now then, that was a mistake. We’re going past a sign and I wanted a photograph of the road sign.
R Oh right. So what did the sign say?
E The sign was Lisdale (pseudonym).
R Uuhh.
E I think she tried to get the next one.
R Ah right.
E Because Lisdale is an important place.
R Uuhh.
E Brian’s (pseudonym, husband) parents live there.
R Yeah.
E And we go there a lot with (business name) as well.
R Ah right. Uuhh.
E So that is an important part of our lives.

This is a quote from the conversation between participant Elizabeth (E) and the researcher (R) in the participant’s final narrative interview. Elizabeth was discussing the significance of why she had included one of the photographs, an interview prompt, and the significance of the place named on the road sign in the image. She had asked her daughter to take the shot whilst travelling in the car with her. A photo-elicitation technique was included as part of the research method, using photographs to encourage the narrative discourse. The conversation quoted above exemplifies the importance of symbolism in the analysis of the photographs, which was a consideration in this research, as opposed to a simple realist interpretation of the content of photographs, which was considered inadequate and would have produced quite different results.

This chapter presents the actual methods employed in the research, including how participants were selected, the design of the narrative interviews and the reasoning behind the selection of the prompt tool utilised in this research, namely the photo-elicitation technique. The analysis procedure is presented in detail, along with ethical considerations and how quality was assured in the research process. Its place in the thesis presented as story is as the final part of the Act II, the development of the plot.
6.2 Participants and sampling

6.2.1 Sample size

Within a positivist research paradigm, to both satisfy the requirements for statistical analysis and for the results to be generalisable and issues such as reliability, validity and prediction would be important to verify knowledge (Denzin & Lincoln, 2003) then a large sample size would have been deemed necessary for the research (Guba & Lincoln, 1989). However, this was a focused qualitative study investigating a number of complex individual life stories of adults whose lives were affected by ABI, where the issues were more centred around empowerment and hearing the voice of the research subjects, rather than producing predictable, generalisable knowledge (Denzin & Lincoln, 2003). Detailed biographical accounts were to be elicited. Typically such experience-centred narrative research uses small samples of participants for this level of study e.g. N=6. Squire (2008) suggests that such research would typically involve more than one meeting, resulting in interviews lasting several hours, which indeed was the situation with this research. Two other PhD theses were considered for comparison of sample size, one researching narratives of women with mental health issues and another researching narratives of men with HIV / AIDS. They utilised a maximum of six participants each thus justifying small numbers in this research (McKay, 2002; Molineux, 2005). This study aimed to collect the narratives of six adults with ABI and six significant others whose lives were affected by ABI i.e. N=12. This was to be later revised if insufficient data was gleaned from the process, but that was deemed to be unnecessary.

6.2.2 Sampling method

Purposive sampling was adopted for this research. Such a technique allowed cases to be selected that had features of the phenomenon under investigation, whilst at the same time demanded careful consideration of the parameters of participant selection (Silverman, 2013). In this research a sample of adults who had ABI, plus a sample of significant others whose lives were affected by ABI, living in rural areas, were to be selected. It would have been inappropriate to include adults in the immediate post-acute phase of the injury, whilst medical symptoms were unsettled. ABI typically has slow recovery and even several years after acquiring a brain injury, occupational gaps are significant (Stilwell et al., 1999; Eriksson et al., 2006). This
justified participants to be included several years since acquiring their brain injury. Indeed this research was interested in their narrated experience of living with an ABI, rather than an event-centred narrative perspective of how the ABI occurred, so a significant time since the event was more appropriate.

Significant others, whose lives are affected by ABI, continue to live lifelong with the impact of the biographical disruption on themselves and the family, with an impact on their occupational balance and occupational engagement, so a time limit was not placed on how long they had lived with a family member with an ABI. Participants had to have the potential to be able to relay their life story e.g. severe cognitive impairment would have excluded them, and significant others had to be willing to tell their own life story, rather than a vicarious discussion of that of the person in their life with an ABI. Only participants living in rural areas were to be included, as per the aim of this research. The consideration of the definition of what constitutes a rural area has been defined in Chapter 1 but can be summarised here as living in a population of less than 10 000 or slightly above if there were poor road and transport links to urban areas or few local services.

6.2.3 Recruitment

Participant recruitment took place through charities for people with ABI, most being affiliated to or suggested by the local Neurological Alliance, of which the researcher had links e.g. Headway. A number of visits took place (to Headway branches, Momentum branches and The Encephalitis Society). Information about the proposed study was summarised in a participant information sheet and was distributed through the charities, either in paper form or on their websites (Appendices A & B). Participants were able to contact the researcher by telephone or email if they were interested in taking part.

6.3 The interview

6.3.1 Interview structure

The interview was carefully considered to enable the elicitation of narrative accounts. In this research the narrative was both the method of data collection and the phenomenon under investigation i.e. a personal experience story (Cresswell,
In order to elicit a detailed personal story from each participant a method of minimal intervention by the researcher was considered to be key. This was to encourage empowering the participant to bring their own interpretation of significant events and experiences to the fore, without being influenced by predefined assumptions on the researcher’s behalf. A compromise had to be found between allowing guidance as to what was the phenomenon of interest (this research coming from the theoretical background of occupation) and how participants interpreted this in the context of their own life experience. The narrative interview had to be such that little attempt was made to suppress the narrative, suggesting in-depth interviews as the method (Mishler, 1986), that allowed participants to explore the meaning of the phenomenon under study for themselves (Elliott, 2005) i.e. engagement in occupations following their life being affected by ABI.

Few descriptions of lightly structured in depth interviews are found in the literature, but the one offered by Wengraf in his ‘Biographic-narrative-interpretive method (BNIM)’ was deemed appropriate and adopted by this research. This was the ‘single question aimed at inducing narrative (SQUIN)’ technique (Wengraf, 2001, p111). It is supposed to stand at the low extremity of interviewer intervention (Wengraf, 2001), which was considered important in this research for empowerment and in order to gain an understanding of how the participants constructed personal narratives in their own minds. More structured narrative interviews would have run the risk of the researcher leading the interviewees in the information they elicited. This single question was;

‘I’d like you tell me about your life, events that have been or are still important to you, including your experience of being married to someone with an ABI. Start wherever you like. I’ll listen and won’t interrupt but will take notes to ask you about afterwards.’

The wording was changed appropriately if the relationship was different to that of married partner or it was the person with the ABI. The principle of not interrupting was to encourage the narrative as it flowed from how it was constructed in the mind of the participant, as opposed to being influenced by detail that the researcher considered significant or interesting (Wengraf, 2001).

Safeguards were put in place to ensure that data produced were not irrelevant and extraneous to the topic (which would have been unethical and time wasting). The
SQUIN technique, if carefully designed, does allow for this and its recommended three-stage approach was utilised in this research. During a second interview the researcher asked ‘narrative pointed questions’ for elaboration on topics that had been raised by the participant, but care was taken not to detract from the narrative by only asking questions about those topics previously raised, using the participant own words and addressing topics in the order that they had been raised. (Wengraf, 2001, p120).

A photo-elicitation technique was introduced to the data collection in the second interview and the resulting images were used in the third and final interview as described in detail in 6.4. This was a prompt to encourage the narrative elicitation with participants that potentially had communication and cognitive deficits. How this technique was selected as the most appropriate prompt tool is also detailed in section 6.4. The focus of third and final final interview was the participant’s occupations, those they engaged in on a daily basis and photographs reflected this, selected and taken by the participant, thus adhering to the focus of the research, which was occupation and narrative.

6.3.2 Piloting the interviews

The success of an interview for data collection can hinge on its smooth running, so were any safeguards put in place to assist with this? Piloting the interviews was considered sensible to refine the practicalities of the research (Silverman, 2013). It also ensured that care had been taken in the research design process to build the credibility of the research. Three mock interviews using the photo-elicitation method took place, with the author’s colleagues, before recruitment began. This was to trial the recording of the interviews and to select the most appropriate method of data collection. It was also to trial the use of a photo-elicitation technique, instruction sheets and use SQUIN interview approach (Wengraf, 2001). Modifications to the technology to be used e.g. recording devices, and approach to questioning, were made as a result. For example, the inclusion of an occupational checklist was initially trialed but subsequently deemed unnecessary; a free-standing camera in the room was found to be clumsy and intrusive and replaced by video recording from the same Apple MacBook that was used to display images that were included in the final interview. The video recording as opposed to simple oral recording added to both context and detail when it came to the data analysis stage.
6.4 **Prompt tools**

The reservation mentioned in Chapter 5, about perceptions of people who have an ABI not being able to meaningfully contribute to research due to cognitive deficits, although rejected as such, deserved some further attention in this research. All of the participants were to be people whose lives had been affected by ABI, living in a rural setting. Some had an ABI, whilst some were significant others in the lives of people who had had an ABI. ABI, in its many shapes and forms, can leave an array of neuropsychological impairments both immediately following injury and long term. These can include cognitive deficits such as attention and memory deficits and impairments in problem solving, dealing with unexpected situations and decision-making (Mazaux and Richer, 1998). This presents a potential challenge to employing a narrative method in research. The narrative is synonymous with story and the narrator draws on a memory of events, selecting and organising them to convey meaning to the listener (Riessman, 2008). If memory, concentration and communication of participants were potentially impaired, careful consideration of the techniques employed in the narrative research method had to take place, indicating that the approach may differ from traditionally reported narrative methods. So how might this be overcome? In order to answer this the literature was explored to select a prompt tool to facilitate the narrative interview.

Any prompt tools considered would ideally serve to facilitate the narrative interview to meet the aims of the research whilst staying as true as possible to narrative methodology principles. For this reason a variety of likely prompt tools were considered: life history grids; art; poetry; photography.

6.4.1 **Life history grids**

Life history grids may potentially have helped people with ABI generate their life story in this research. In narrative research often the subject will demonstrate an impulse to elicit lengthy accounts at unexpected times. In order to facilitate this, the investigator must relinquish control, which can generate a degree of anxiety (Riessman, 2008), especially in this research where some participants were cognitively impaired and had limits on social interaction. A balance needed to be struck between suppressing the narrative impulse and encouraging storytelling. Sometimes a wide time frame presented to a respondent can be daunting and the
use of life history grids may serve to ease talking about events (Elliott, 2005). In this research a dilemma was presented between relinquishing control of the interview and prompting to encourage storytelling of the individual’s own life history. Elliott encourages the use of the life history grid in such situations, where a completed grid can be used in subsequent interviews for recounting life history from whatever point is appropriate for the respondent. Columns of the grid can relate to the focus of the research and whilst the dates are not important they can help to order events (Elliott, 2005).

Published research on life history grids suggests that their utility encourages relationships (Parry, Thompson & Fowkes, 1999; Wilson, Cunningham-Burley, Bancroft, Backett-Milburn & McMasters, 2007). This aspect was considered for this research as the relationship encourages the narrative in terms of the emotional attentiveness offered by the interviewer and the degree of reciprocity in the conversation (Riessman, 2008). However, there have been conflicting accounts of whether or not they assist in the discussion of sensitive topics (Wilson, Cunningham-Burley, Bancroft, Backett-Milburn & McMasters, 2007; Bell, 2005). It has been suggested that the event-centredness of the grid can produce non-reflexive data and stimulate recall in a limited fashion (Bell, 2005).

The facilitatory nature of life history grids is well-documented, in terms of improving accuracy of recall (Blane, 1996; Parry, Thompson & Fowkes, 1999.) This factor was less important in this research, where the mimetic or realist stance was less of a priority than the emplotment of the narrative: revealing a window on the psyche, with story told from the participant authoritative point of view, already knowing the beginning, middle and end of the story was prioritised here (Mattingly, 1998). Life history grids were thus not utilised in this research.

6.4.2 Art

Narrative research has been undertaken involving the topic of art, though mainly with respect to exploring how art therapy and art-making has impacted on the lives of people with illness, specifically breast cancer or mental health issues (Collie, Bortoff & Long, 2006; Stickley, Hui, Morgan & Bertram, 2007; Reynolds, Lim & Prior, 2008). Art has been found to trigger memories and release emotional pain (Collie, Bortoff & Long, 2006) and assist in respondents gaining insights into their lives and help make identity clearer following serious illness (Collie, Bortoff & Long,
However, this was in longer-term art endeavours than were to be considered in this research, and therapy-centred, which this research was not. The aim here was to have a prompt tool for the narrative interview, rather than engage in a therapeutic intervention. Thus art was not adopted as a prompt tool.

6.4.3 Poetry

Poetry may also have utility in narrative research for those affected by ABI. Poetry offers an opportunity to convey the emotive elements of the human experience. It is claimed that the brevity of poetry and the corresponding metaphor are some of the features that make it a powerful tool. The metaphor is more powerful than the photograph as the reader is forced to create their own image, moving them out of passivity into engagement (Furman, 2005). Poetry offers paradoxes about life and in turn these paradoxes have been likened to the paradoxical issues discussed by Erikson in his life-stage theory, in that it is the resolution of these paradoxes that bring the individual to the stage of integrity (Edwards, 1990). Irrelevant detail is weeded out through the condensed narrative offered by poetry. Any poetry used to enlighten a narrative provides a plot to the narrative and a philosophical seriousness, as opposed to a historical recollection, which would merely be linked facts (Mattingly, 1998).

The power of poetry has been harnessed in a number of differing ways in healthcare research. Rosenblatt suggests that published collections of poems can be utilised by researchers and theorists as bone fida research data (Rosenblatt, 2011). Generating poetry has been found to produce rich contextual and emotional data in the form of poetry and metaphor for analysis in doctoral studies with children diagnosed with Attention Deficit Hyperactivity Disorder (Prosser, 2009). Similarly autoethnographic research has utilised poetry as both the subject and product of inquiry, in the areas of study of death and depression (Furman, 2005; Gallardo, Furman and Kulkarni, 2009). The approach of analysing narratives in the form of poetry was also used with patients with heart failure and their carers (Kendall & Murray, 2004), in the form of oral poetry as opposed to stylised formal poetry written down. Responses to the poetry were found to be different to prose due to natural conditioning to responding to poetry alternatively.
All things considered, would it be a useful prompt tool in this research? One of the disadvantages to using poetry in this research was that from a contemporaneous point of view fewer people read or write poetry than in previous generations. This consideration may be enhanced in the lower socio-economic area of north-east England, the predominant location of this research. Potentially this was a barrier in terms of initial engagement with becoming a participant. Due to keenness to make recruitment easier poetry was a trigger worthy of consideration, especially due to its prolific use in narrative research, but less attractive than such as the popular medium of photography, to which attention now turns.

6.4.4 Photography

Finally, photography was considered as a potential prompt tool. Photographic images and other visual tools have enjoyed a popular space as a research instrument in narrative inquiry in the last two decades, prior to which a words and numbers based approach to research dominated the social sciences (Prosser & Loxley, 2008). Still pictures and video-diaries have been used in both individual and collective research studies, with the visual imagery produced being used as both trigger to produce data, the actual data itself or a combination. One of the key attractions to using this type of visual method was the participatory aspect for the subject of the research, promoting empowerment and allowing a focus on the issues defined by the research subject as opposed to those considered important by the researcher (Prosser & Loxley, 2008). Documentary-type images on human-interest topics, produced for general public consumption, place the visual image at the end-point of knowledge production, but in this research the concern was with the visual image representing the mid-point in knowledge production in social science research, as a prompt or trigger, or data for analysis (Luttrell & Chalfen, 2010).

There is an advantage in asking the participant to create the images as opposed to the researcher. Researcher-created images have been linked to a positivist realist approach to research, purporting to objectivity. However it could be said that if the researcher is reflexive about how the image is produced and the images are indeed subjective, phenomenological introspection may reduce researcher bias (Prosser & Loxley, 2008). Where the participant decides on what to produce an image of and what meaning they give to it is labeled a feminist approach to research (Prosser & Loxley, 2008). When participant generated photographs are used as prompts in gathering qualitative data (photo-elicitation), it can be said to exploit the power of the
relationship between pictures and voices and especially assist in giving voice and empowering people who are marginalised (Luttrell & Chalfen, 2010). This appealed to adopting it in this research. Furthermore, in situations where the participant makes decisions about what visual images to produce it can produce a counter-narrative to that presumed by the researcher, again, appealing to this research (Harrison, 2002). Thus, it was considered that this research, where some adults had potential cognitive issues associated with ABI, might well benefit from undertaking a photo-elicitation method, where they would be given cameras to identify aspects of their lives in a photobiography approach, which can explore issues of personal identity (Harrison, 2002).

However, our visually rich culture, with populist imagery generated through the media, may influence how images are constructed and lives portrayed and could have interfered with the method in this research. Photographs from family albums have been constructed with a future audience in mind and attesting to social relations and social practice, such as holidaying in desirable locations (Harrison, 2002; Prosser & Loxley, 2008). Indeed, they would not have been produced with research in mind. Giving participants cameras to record images or events of their everyday practice has been a common approach in more recent narrative research (Lorenz, 2010; Chard, Faulkner & Chug, 2009). This looks to the photographs no longer being used as self-representation, as in holiday snaps and formal pictures in family albums, but to more of an approach that communicates a self-presentation of everyday life (Slater, 1995). This fitted well with the research requirements here.

Photo-elicitation techniques have been utilised in research with adults with ABI. Disposable cameras issued to participants generated photographs about daily life and the lived experience. Benefits of adopting the method were found to be numerous: it puts biographical disruption into perspective; can be therapeutic from the point of view of promoting empathy; it helps uncover a new identity and meaning of life for the participant (Lorenz, 2010 & 2011).

In summary, the photographic image had the potential to serve as an aid to narration of the life story, by prompting memory or communicating everyday experience about social practice and social relations. This was of particular value to this research, where some participants had cognitive impairments in terms of memory deficits or verbal communication. Participant-generated photographs had the benefit of empowering the participant to bring to the fore issues of significance
for themselves as opposed to those issues pre-supposed by the researcher. It was thus adopted.

At the end of the second interview participants were given a camera and instructions on how to use it, plus details of the type of image to generate, which can be found in Appendix C: Instructions for the final interview. Everyday images of typical occupations were of interest here and participants were asked to take approximately ten photographs of typical activities that they did in a day or filled their time with during the week.

6.5 Assuring quality in the method

6.5.1 Reflexivity

Various approaches addressed confirmability in the research (likened to objectivity of quantitative research), (Guba & Lincoln, 1989). One aspect of this was by the researcher declaring their positionality, as described in Chapter 5. Not only was this declaration made, but also the underlying principles behind this were carried forward within the research, considering how the researcher’s background may have influenced the data gathering and analysis. A reflexive diary was thus employed before, during and after each interview (including the mock interviews) and as the analysis procedure got underway (McKay, Ryan & Sumsion, 2003). This facilitates a scrutiny and analysis to the knowledge claimed by the researcher (Blair & Robertson, 2005). Further reflexive accounts came from informal meetings with research participants, such as initial encounters at charity meetings. One extract from the final interview with participant Rachel is offered below:

“This immediately set her off talking about her love of (rock band) and the lead singer. She began walking around the room to find a photograph of her with him, taken after a gig and then showed me the tattoo on her arm, which was of him with a special signature of his from the photograph. Afterwards I began to think about my relationship with tattoos. I now know that I must automatically relate to the overall visual image of a person e.g. ‘what a shame that person has a tattoo that gets cut in half on her arm when her sleeve lands halfway down it’. I began to think about the relationship she has with hers and it must represent a badge of honour. This tattoo represented not only a man she had idolised (and had done so for 25 years plus), but his connection with her (the signature) and that statement she made about his music being very deep and meaningful. This refutes my own previous view of tattoos being there to be aesthetically pleasing – a huge insight for me personally. Perhaps I need to look more closely when I see a tattoo and think that perhaps it adds something to someone’s life narrative and makes them more interesting than someone who is simply aesthetically pleasing!”
The above is an example of utilising reflexivity to challenge the researcher’s authoritative voice, through ‘ironic deconstruction’ (Finlay, 2003, p14). The reflexive accounts were utilised before the analysis of each set of interviews.

### 6.5.2 Credibility, transferability, dependability and confirmability

Additional tactics were employed to further satisfy the requirement for quality in this research, especially as the relativist position adopted promotes the idea of multiple realities (for example, those in addition to the researcher). The researcher had prolonged engagement with the participants, allowing for detailed and free-flowing accounts from participants (Collingridge & Grant, 2008). The careful design of the methods facilitated this, including the SQUIN and preparation in terms of the mock interviews.

The issue of verification in terms of the credibility of research was carefully considered. It is suggested that if participants were asked to verify their story the principle interest would be in the mimetic value of the story, rather than the storyteller’s intended creativity on relaying reality (Frank, 2010). This discouraged verification and returning stories to participants. Additionally, as a theoretical analysis was undertaken on the narrative interviews it could well have complicated any understanding of material returned to participants and their understanding of it (Ballinger, 2004). Some participants discussed sensitive issues concerning partners e.g. abuse, suicide, and there was no easy way to return interpreted life stories for verification ethically, (for example the husband held the only email account). For this reason a compromise was struck, as verification was still considered a key tool for credibility. Stories were returned to three participants where there were none of the complicating factors just mentioned: the rewritten life stories were returned (the results of narrative analysis), as opposed to the cases at the theoretical stage of psychological analysis (analysis of narrative). In addition to this the researcher’s Director of Studies engaged in an independent analysis of one additional participant’s data. A record of comments from two participants who had their story returned can be found in Appendices D and Q.

Transferability of this research was considered by including rich descriptive contextual data in the narrative analysis (Lincoln & Guba, 1985). It is not claimed that the research results produced here are valid or truthful for others in the same situation, with this being relativist research. Providing context in which the data were
gathered however, allowed for transparency behind the interpretation of this researcher (Ballinger, 2004). The details of participants’ personal situations are offered both in Chapter 7, Table 1 (Participant Demographics) and within the constructed narratives themselves. Appendix E (Table 5) also offers an audit in terms of length of actual interviews.

Care was taken to ensure that what was said in the interviews was carefully represented in the interview transcripts. Careful consideration needed to be given to this before the process of transcribing began (Davidson, 2009) to assist with the research process appearing to be dependable from a research quality perspective and was indeed undertaken. Seminal work by Ochs (1979), from the perspective of a linguistic researcher, advocates that the approach to transcription is best considered with theoretical goals of the research in mind. Often, a theoretical preparation for transcription is not considered and bypassed. The very process of transcription and by virtue of having different ways of approaching it, removed the idea of producing a true object (Duranti, 2007). Refusing to accept that the transcript is a constructed entity could be considered to be taking a positivist approach to this stage of the research process. In this research, it was acknowledged that choices had to be made about how to transcribe in order to meet the research objectives and no one toolkit was perfect (Lapadat, 2000).

Firstly enough detail was included so as there was sufficient data for analysis: it had to be representative of the interview, but if the material were too detailed it would cloud the process of analysis (Ochs, 1979). It was decided not to include contextual information at key points of the transcription, such as the length of pauses and voice tone as when the analysis process was carried out it drew on both the transcripts and repeated viewings of the interview video tapes, thus deeming the fine detail superfluous (Duranti, 2007). The inclusion of all utterances, pauses, ‘ums’ and ‘ers’ etc. was considered important, with little tidying of the text. This naturalist approach with verbatim speech best served the aspect of this research that sought to uncover the performative aspect of the participant’s life story (Oliver, Serovich & Mason, 2005). Two of the interviews were transcribed by the researcher (out of interest and to familiarise with the peculiarities of transcription), whilst the majority were transcribed by an individual who had several years experience as a professional transcriber. Discussion took place with the transcriber before commencement as to the approach to be adopted.
Care was also taken to ensure that the voice of the participant was generated in the photo-elicitation technique. A significant other person might have influenced what to include and what to omit in the gathering of the photographs between interviews two and three (Harrison, 2002). Instruction made clear that any photographs collected by participants were what they particularly wanted to capture rather than another person in their daily life (Luttrell & Chalfen, 2010).

Standing up to scrutiny of academic audiences adds to the quality aspects of the research (Riessman, 2008). Four oral presentations to academic audiences were given during the research process to assist with confirmability: a University of Teesside Health & Social Care Research Institute seminar (September, 2014); Occupational Science Europe Conference (September, 2015); International Visual Methods Conference (September, 2015); British Medical Sociology Conference (September, 2016).

6.6 Researching ethically

Ethical considerations were taken into account in this research and steps were taken to minimise risk or harm to both the participants and indeed the researcher. As with quantitative research, this qualitative project needed to consider the issues of voluntary participation, protection of participants, assessment of benefit and risk and informed consent (Silverman, 2013). The first consideration was that the research design was robust and consistent with defined parameters. Also participants had to have mental capacity to give informed consent and not agree to take part in any activity that they were not fully aware of potential consequences. For this purpose a participant information sheet was given to each interested party (Appendix A). This was available in the form of both a flyer and simple Microsoft Word document (Appendix B) for those who may have difficulty following the layout of the flyer, due to cognitive difficulties. During meetings attended by the researcher to invite engagement with the research care was taken not to coerce participation and the researcher refrained from approaching individuals directly. Any interested individual was screened to ensure that they met the inclusion criteria, so as there was no gathering of research data that would not be utilised and thus had been gathered unnecessarily.
Consideration was given to where the interviews were to take place, as this had the potential to influence the narrated story. This occurred at locations convenient to both the participant and researcher so as not to inconvenience participants. For example, one participant did not want to disrupt her husband’s routine by being interviewed at home so a private room in the local leisure centre was utilised. Ten participants chose to be interviewed in their own home and one at the local university. Travelling to unfamiliar rural areas, usually to participants’ homes could have posed a potential risk to the researcher. To reduce this risk details of venues were left in a sealed envelope with a third party and checking in with the third party before and after the interview was done to assure safety and the envelope then destroyed.

Informed consent was recorded on two copies of a consent form (Appendix F) with each participant assigned a unique identifier number of which they had access to. This would have allowed participants to withdraw their data within one month of data collection, should they so wish, having considered that they only revealed to the researcher what they wished to reveal. A debrief sheet (Appendix G) was left with each participant following the interviews incase they revealed matters that distressed them.

Anonymity of the participants was assured by disguise of real names, locations, particular organisations etc. mentioned in the interviews. Actual first names were put into an internet search to find names that were popular at the same time as participant’s actual names, to keep fidelity to the narrative context. Additionally confidentiality was considered by storage of data undertaken with due care and attention, by use of a password protected laptop and back-up copies in a locked cupboard.

The use of the photo-elicitation method did present ethical issues for this study. It is suggested in the published literature that ethical issues around the use of photography in research could be more fully explored and debated. Few exemplary case studies of photography-based research were available on which to base decisions. Commonly adopted protocols do not fit with a visual approach and there is a danger that over-bureaucratic approaches may end up being adopted (Prosser & Loxley, 2008). Cameras handed over to participants may reveal illegal acts or dangerous practice and anonymity of those photographed must be considered (Prosser & Loxley, 2008). Wang & Burris (1997) suggest investing training time with
participants at the beginning of the project discussing cameras, ethics, power and ownership of the images. Indeed in this study a discussion took place at the end of the second interview when the camera was left with participants. The purpose of the procedure was explained, along with a request not to include others in the image, as the researcher could not be certain of gaining consent from third parties.

Ownership of the images and restrictions placed on how participants self-represent offer further ethical consideration (Luttrell & Chalfen, 2010). It was explained to participants how the images would be used and that if utilised in publication steps to ensure anonymity would be taken. Provision was made for both parties to have ownership of the images and indeed two participants asked for electronic copies and another asked for paper copies, all of which were given.

Ethics approval was granted through the Teesside University ethics procedures, namely the Research Ethics Committee of the School of Social Sciences and Law (December, 2012) (Appendix H).

**6.7 Methods of analysis**

**6.7.1 Analysis of narratives in general**

With Mishler’s concern of a state of near-anarchy over what constitutes narrative (discussed in Chapter 5), it left a dilemma as to an agreed way to proceed with the analysis in this research. Indeed, diversity in proceeding with analysis is advocated (Mishler, 1995; Hanninen 2004). So what options and considerations were drawn on to select a method of analysing narratives in this research, particularly an appropriate method for experience-centred narratives of people whose lives had been affected by ABI, living in rural communities?

The focus of interest in the research should always influence the approach to analysis in narrative research. For example there may be an interest in the told narrative itself or a phenomenon under study, with emerging issues (Hanninen, 2004). The focus of this study was both, a) individual narratives as well as b) the phenomenon under study, that being a) the emplotted stories of individuals whose lives were impacted by ABI living in rural communities and b) how they structured their narratives in terms of their engagement in occupations. The SQUIN method
utilised in the interviews is accompanied by a highly structured and detailed method of analysis, the Biographic-Narrative Interpretive Method (BNIM), rigorously defined and sequenced, which requires a research panel to work on hypothesising and counter-hypothesising. However, it is acceptable to use the BNIM to gather data but use alternative ways of interpreting the material (Wengraf, 2001). As this study did not have access to a collective panel to work in fine detail on the data, this method was not the one selected for analysis. Other approaches to analysis, such as a Labovian approach, were also considered but rejected, on the basis that it is more appropriate for event-centered narratives (narratives in this research were experience-centred) and it takes less account of context (Patterson, 2013).

This research involved the inner narrative. It was unknown as to what was psychologically true in the narrative and how much social conventions influenced the delivery of the story (Hanninen, 2004). People internally view themselves in terms of stories and the told narrative may have been influenced by a cultural stock of stories (from such as gossip, novels, fairytales and the media) and the individual’s personal stock of stories (Polkinghorne, 1998; Hanninen, 2004). In the case of this research, where some participants were individuals with an ABI, the personal stock of stories may also have been limited due to cognitive issues. Additionally, participants may have wished to reveal alternative interpretations or resist dominant cultural story models about such as disability and stigma.

Participants would have been selective in what they choose to recall from memory, as we are unable to experience life itself, from a psychological perspective, irrespective of any cognitive deficits (Bruner, 2004). There is little consensus on how the inner narrative is a representation of the told self-narrative, but it is acknowledged that there are very close links. A closer link was potentially encouraged by the method in this research with minimally structured narrative interviews (Hanninen, 2004). Individuals would have had varied public versus private display of psychological attributes in the interviews. For example the degree of personal agency would have influenced the means by which they discussed issues, influenced by their cultural expectation and circumstances at that particular time (Harré, 1983).

Certainly any analysis needed to look further than the content of the narrative, to the discourse used and what intentions lay behind the telling of the narrative. It needed to encapsulate all three functions of narratives: meaning, structure and context.
(Mishler, 1995; Elliott, 2004). Plots would have been developed against a backdrop of social, cultural and historical contexts and the story’s performance would have been dependent on to whom it is told and why, all suggesting the imperative of close reading or interrogation of the texts (Riessman, 2008).

So in the analysis of this research the purpose was to re-present the narratives and reveal the plot behind these. There was an additional layer to the analysis considered too, which was an attempt to decode the narrative to reveal concepts, structures and disguised meaning. These two approaches could be considered a hermeneutics of faith or a hermeneutics of suspicion (Ricoeur, 1988; Josselson, 2004). Indeed this research aimed to do both, to give voice to the participants (meaning), whilst at the same time offering explanation beyond the text (structure, in this case to consider engagement in occupations). Thus the method of analysis was guided by these two principles.

6.7.2 Narrative analysis and analysis of narratives

A multi-modal approach to analysis was adopted in this research, acknowledging the importance of linguistics whilst stressing the significance of some statements being context sensitive (their meaning could have been altered and lost if broken down too specifically in analysis). Pattern recognition and analogy were considered crucial to meaning-making. The narratives were analysed using two approaches, each linking to one of the two modes two of cognition (narrative and paradigmatic); a narrative analysis drew on narrative cognition to expose the narrative reasoning and an analysis of narratives drew on paradigmatic cognition to expose the paradigmatic reasoning (Polkinghorne, 1995b). The narrative analysis brings the unique experience of life lived to the research; the analysis of narrative brings categorisation of lives lived. Both are derived from the cognitive processes of the participants (Bruner, 1986; Polkinghorne, 1995b).

6.7.2.1 Narrative analysis

Narrative analysis involves studying the data to produce a story or stories, which in this research, constituted a series of case studies. Analysis of the narrative mode of cognition takes place. The life story is reconfigured, so as to identify the intended thematic plot of the participant’s story. Here, sections of data provided in the research interviews were connected and temporally re-ordered, before the story was
drawn to a conclusion (Polkinghorne, 1995b). The data for analysis came from the interviews, observation of the video recordings, the photographs produced by the participant and consideration of the reflexive diary of the researcher. Data were selected that advanced the participant’s intended plot. Data not significant to the plot was dispensed with, unless it contradicted the plot, in which case revision of the plot was required (Polkinghorne, 1995b). Participants told their story out-with a temporal ordering of events and with a number of digressions, as is typical in this type of research, and potentially heightened for some participants if cognitive issues were apparent. To this end the researcher attempted to reconstruct the participant’s story putting the events together in chronological order, in order to reconstruct what was told and how it was intended to be told (Mishler, 1995). Thus the muddled happenings in the interviews were reconfigured into a temporally-organised whole. Without emplotment, the data could not be considered to be a narrative.

In the analysis of this research, synthesis, rather than separation of data was undertaken, to acknowledge the importance of context. The resulting story was more than a representation of events and reflected that at the time of telling, the outcome of those events was known and human purpose and choice had been injected into the story. The choices and actions of the central person in the story, within a bounded temporal period, were revealed. The overarching result was an explanation of how an outcome came about. The finished product offered a meaning that is not overtly apparent in the data as it was presented. Each emplotted story revealed idiosyncrasy, complexity and uniqueness (Polkinghorne, 1995b). Thus twelve individual emplotted stories were generated from the data by this approach to analysis.

6.7.2.2 Paradigmatic analysis of narrative data

Analysis of narrative involves studying the data for purposes other than emplotment and production of a story. It is a form of paradigmatic analysis, drawing on the paradigmatic mode of cognition and in contrast to narrative analysis, produces themes and concepts across cases (Bruner, 1986). It was adopted in this research alongside the narrative analysis. This allowed the research to reveal how participants structured their narratives and themes occurring across cases relating to engagement in occupations. Temporality and the sequence of events were still pertinent in this approach to analysis.
Any concepts and themes generated by this analysis can come from existing theories, for example, concepts such as assigning typologies to narratives, where commonalities are identified across cases (Polkinghorne, 1995b). An example is Frank’s early approach to considering the career of an illness in a narrative and what happens to people at each stage of their illness. Typologies of core narratives can then be assigned to individual stories, for example the chaos, restitution or the quest narrative (Frank, 1995). Analysis of narrative in this research involved consideration of the existing theoretical concepts of narrative tone (McAdams, 1993); typologies of restitution, chaos or quest (Frank, 1995); progression, stability or regression of the narratives (Gergen & Gergen, 1986) and literary genre (Frye, 1957).

Not only can a thematic analysis of narrative produce concepts and themes from existing theory as described above, but themes can be generated inductively too (Polkinghorne, 1995b; Braun & Clarke, 2006). A thematic narrative analysis should look at what and how content is communicated in the narrative (Riessman, 2008). In this study, analysis of narrative involved identifying themes within each case study, as well as across case studies, having employed both narrative psychological analysis approach (Crossley, 2000a) (see 6.7.3) and Braun & Clark’s (2006) approach to thematic analysis.

6.7.3 The steps in the process of analysis

The steps of the process of analysis were strongly influenced by, though adapted from, Crossley’s proposed structure from narrative psychology, which drew together many of the theoretical concepts behind this research (Crossley, 2000a). This narrative psychology approach goes beyond a social constructionist discourse analysis to also consider personal subjectivity (Crossley, 2000b). The following steps were taken in the analysis procedure overall, for each participant;

(i) transcripts read for overall gist (in conjunction with video data and reflexive diaries)
(ii) data organised by elements of the SQUIN i.e. life story; events; experience of living with ABI; activities; roles; rural living
(iii) photographic analysis
(iv) identification of narrative tone
(v) data organised in a coding frame for analysis
(vi) each narrative written as an emplotted story (narrative analysis)
(vii) individual ‘analysis of narrative’ conducted
(viii) narratives ‘allowed to breathe’ for emerging themes (inductive analysis within narratives and themes across whole narratives)

The coding frame in step (v) was designed to draw out meaning and issues pertinent to each narrative (Murray, 2015) (Appendix I). The frame was underpinned by a number of concepts from narrative theory and issues pertinent to the aims of the research. Firstly, one approach in the literature on occupational identity had identified progressive, stable and regressive elements of participants’ life courses, based on Gergen & Gergen’s narrative structure (1986), as well as drawing on imagery through the discourse (Braveman & Helfrich, 2001). Both of these concepts were included in the coding frame here. Socially shared stories (for example how disability is represented) were considered by taking time to consider anchoring and objectification in the discourse (Murray, 2000). The context of the interview and positional aspects of the interview being held with this particular researcher (and analysed by her) warranted consideration in the coding frame too. McAdams’s concepts of narrative tone and the values and beliefs coming through in the narrative (such as power and agency, love and relationships) were also included (McAdams, 1986; Crossley, 2000a). Finally, the topics of the content of the narratives were included in the coding frame, drawn from the constructed SQUIN, such as activities and roles at various stages of the life cycle and occupational theoretical concepts apparent. This multi-factorial approach aimed to produce what can be described as ‘emancipatory narratives’ (Murray, 2000).

6.7.4 Analysis of photographs

The main purpose of the photo-elicitation was to produce a prompt for the narrative interview to reveal engagement in occupations. Initially this was with participants with ABI in mind, where potential memory impairment or lack of clarity in both flow and explanation might have been apparent. However, it was adopted with all participants, to promote sharing of insights and understandings. The photographs produced by participants constituted additional data to accompany the verbal narrative. They provided contextual information and subjective perspectives in the narrative (Kolb, 2008). Due to the cognitive impairments of some participants, the photographs produced by the participants revealed data that otherwise may have
remained hidden. So what method of analysis was utilised for the photographic data?

Cronin (1998) raises the issue of the photographic image being realist or symbolic. The realist or empirical approach assumes that the photographic image represents an objective reality. A relatively simple content analysis could be conducted if the realist approach were accepted. This is in contrast to the symbolic image, which requires interpretation, either by the photographer (in this case the participant) or the researcher, at the level of discourse (Caplin, 2005). The symbolic approach draws on Potter and Wetherall’s (1998) social psychology theory and required the researcher to consider what the participant was aiming to represent in their production of photographs and subsequent discussion. Thus, both the content and the context of the photographs were significant: the content being the internal narrative and the context being the external narrative (Banks, 2001).

The recognition of the participant as an analyst and not merely as a data producer could be overlooked but was important in this research (Jenkings, Woodward & Winter, 2008). The photographer produced a personal record of their engagement in daily occupations. This could run the risk of producing an impersonal record that the researcher might have attributed different meanings to, if not further explored with the participant (Grady, 2008). The accompanying discourse to any photograph would be bound up with the values of the participant and thus important (Caplin, 2005).

This aspect of photo analysis was taken still further to promote a reflexive consideration of the collaborative act taking place during the requesting of photographs and the subsequent discussion between participant and researcher (Jenkings, Woodward & Winter, 2008). Therefore analysis of the photographs as data was undertaken using a joint realist, symbolic and reflexive approach. How the participant explained the content was dependent, to a degree, on the interaction between participant and researcher, in that the discourse was co-created. This methodological approach has goodness of fit with the narrative mode of cognition, where the story produced is part of the emplotted narrative and co-constructed by the presence of the interviewer. The photographs produced became both part of the narrative analysis and analysis of narrative (Polkinghorne, 1995), significantly contributing to the overall analysis. The photographic images illuminated the narrative analysis or emplotment of the story by both their content and the verbal
dialogue. New information came to the fore that was not immediately obvious from the image alone, for example about social activity and social rules (Kolb, 2008). Consideration was given to the fact that interviews took place in the context of certain seasons and over a period of one week in the life of the participant, which therefore limited the content to a brief period of their lives. Engagement in other activities was discussed alongside photographs and thus the realist element of the photographic image required additional data from the discourse. Thus any procedure for analysis of the images was required to take discourse into account also. Collier & Collier’s (1986) Basic Model for Analysis was adapted as the process for analysing the photographs as data to complement the analysis of the interview discourse (Appendix J).

6.8 Chapter summary

This chapter presented the actual procedure of the research study and its assurance for robustness. Details of not only sampling and recruitment were presented, but a transparent and auditable trail of the interview structure and how it was piloted. The reasoning behind the choice of the photo-elicitation approach adopted was discussed and why alternative methods were rejected. Quality issues were addressed, including how care was taken to work reflexively and ethically. The chapter concludes with the development of the analysis procedure, which embraced a coding frame and photographic analysis. The plot of the story of this thesis now proceeds to Act III to present a form of ‘resolution’ to the exploration of issues relating to the disruption of narrative, occupation and identity due to ABI.
Chapter 7  The stories analysed: Narrative analysis aspects

7.1 Introduction to the chapter

“I have, I am aware, told this story in a very rambling way so that it may be difficult for anyone to find their path through what may be a sort of maze. I cannot help it. I have stuck to my idea of being in a country cottage with a silent listener, hearing between the gusts of the wind and amidst the noises of the distant sea, the story as it comes. And when one discusses an affair – a long, sad affair – one goes back, one goes forward. One remember points that one has forgotten and one explains them all the more minutely since one recognizes that one has forgotten to mention them in their proper places and that one may have given, by omitting them, a false impression. I console myself with the thinking that this is a real story and that, after all, real stories are probably told best in a way that a person telling a story would tell them. They will then seem most real.”

Ford, 1910, p134.

The above is an extract from *The Good Soldier: A Tale of Passion*, an acclaimed work of twentieth century fiction by Ford Madox Ford. It illustrates the way by which, when people tell their narratives, they fail to follow a logical and time ordered sequence, they remember nuance and detail to be included that they had forgotten to mention earlier and return to it later in the telling for completeness. It mirrors the experience of the participants in this study in the telling of their life story to the researcher. Part of the task for the researcher was to re-order and re-present the participants’ life stories, underpinned by the intended plot.

This chapter aims to present the demographics of the twelve participants and offer an account of how one participant’s data were handled for the analysis. Two stories, analysed through the process of narrative analysis (Polkinghorne, 1995b), are presented, selected due to being representative of the lived experience of one individual with ABI and one significant other.

7.2 The research participants and the handling of the data to write the stories

Each of the twelve participants underwent three interviews. Basic demographic data emerged from the interviews and is presented in Table 1. Following transcription of the interviews a longitudinal inquiry began. The steps taken in this iterative process
of analysis are described in Section 6.7.3. An example is offered by way of Angie’s Case study:

Angie was 38, lived in a small village and had an ABI following encephalitis when she was eighteen. She underwent the three interviews, including the photo-elicitation technique. Once her transcripts had been numbered they were read and reread by the researcher for an overall gist. The video recordings of the interviews were viewed simultaneously and the reflexive diary was read in conjunction.

Table 1: Participant demographics

<table>
<thead>
<tr>
<th></th>
<th>Pseudonym</th>
<th>Gender</th>
<th>ABI or significant other</th>
<th>Age</th>
<th>Time since injury (years)</th>
<th>Type of injury</th>
<th>Rurality</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rachel</td>
<td>Female</td>
<td>Significant other</td>
<td>53</td>
<td>9</td>
<td>Brain tumour</td>
<td>Small rural town</td>
<td>Married</td>
</tr>
<tr>
<td>2</td>
<td>Sam</td>
<td>Male</td>
<td>ABI</td>
<td>51</td>
<td>9</td>
<td>Brain tumour</td>
<td>Small rural town</td>
<td>Married</td>
</tr>
<tr>
<td>3</td>
<td>Angie</td>
<td>Female</td>
<td>ABI</td>
<td>38</td>
<td>20</td>
<td>Encephalitis</td>
<td>Village</td>
<td>Single</td>
</tr>
<tr>
<td>4</td>
<td>Bruce</td>
<td>Male</td>
<td>ABI</td>
<td>45</td>
<td>5</td>
<td>Traumatic brain injury</td>
<td>Remote rural</td>
<td>Married</td>
</tr>
<tr>
<td>5</td>
<td>Susan</td>
<td>Female</td>
<td>ABI</td>
<td>54</td>
<td>8</td>
<td>Sub-arachnoid haemorrhage</td>
<td>Small rural town</td>
<td>Married</td>
</tr>
<tr>
<td>6</td>
<td>Hilary</td>
<td>Female</td>
<td>ABI</td>
<td>54</td>
<td>10</td>
<td>Sub-arachnoid haemorrhage</td>
<td>Village</td>
<td>Divorced</td>
</tr>
<tr>
<td>7</td>
<td>Helen</td>
<td>Female</td>
<td>Significant other</td>
<td>46</td>
<td>4</td>
<td>Stroke</td>
<td>Village</td>
<td>Married</td>
</tr>
<tr>
<td>8</td>
<td>Christopher</td>
<td>Male</td>
<td>ABI</td>
<td>47</td>
<td>23</td>
<td>Brain tumour and stroke</td>
<td>Village</td>
<td>Single</td>
</tr>
<tr>
<td>9</td>
<td>Doug</td>
<td>Male</td>
<td>Significant other</td>
<td>71</td>
<td>12</td>
<td>Embolism</td>
<td>Remote rural</td>
<td>Married</td>
</tr>
<tr>
<td>10</td>
<td>Elizabeth</td>
<td>Female</td>
<td>Significant other</td>
<td>55</td>
<td>37</td>
<td>Traumatic brain injury</td>
<td>Remote rural</td>
<td>Married</td>
</tr>
<tr>
<td>11</td>
<td>Diana</td>
<td>Female</td>
<td>Significant other</td>
<td>77</td>
<td>16</td>
<td>Traumatic brain injury</td>
<td>Village</td>
<td>Widow</td>
</tr>
<tr>
<td>12</td>
<td>Rita</td>
<td>Female</td>
<td>Significant other</td>
<td>44</td>
<td>48</td>
<td>Encephalitis</td>
<td>Remote rural town</td>
<td>Married</td>
</tr>
</tbody>
</table>

Here is a brief excerpt from the reflexive diary of Angie’s Interview three:

“I was aware that this participant came from a similar social background to myself (despite age differences). I need to be careful not to make further assumptions based on my background because of this.”

Considerations such as this were taken into account in the analysis. An outline of the process of the analysis of Angie’s data is offered here with details in Appendix K.
Data needed to be drawn out of Angie’s transcripts relating to the elements of the SQUIN: questions were asked of the transcripts such as, ‘Which elements of this transcript relate to her life story? Which significant events took place in her life? What is her experience of living with ABI? What activities does she take part in? What roles does she hold? What is her experience of rural living and ABI?’ These data were recorded in a series of six tables, (Tables 5 – 10), which can be seen in Angie’s case as Appendix K: Examples of Narrative Analysis Tables. Angie’s fifteen photographs (Appendix L) were analysed and recorded in the photographic analysis template, bearing realist and symbolic aspects in mind (Appendix M, Table 11).

Consideration to the tone of Angie’s narrative was then given and it was decided that in her case it was predominantly pessimistic (McAdams, 1993). Although overall it was deemed a stable narrative (Gergen & Gergen, 1986), it was considered to carry a genre of tragedy (Frye, 1957) and could potentially be classed as a chaos narrative in that despite her day to day coping and stability, restitution appeared longed for but had not been achieved and only some minor elements of quest were evident (Frank, 1995).

The analyses described above were then accumulated into a coding frame for analysis (Crossley, 2000a) (Appendix N, Table 12). From this Angie’s emplotted story was constructed to complete the narrative analysis (Appendix O) and a further analysis of narrative was undertaken (Appendix P). Analysis of narrative is the focus of Chapter 8 (Polkinghorne, 1995b). Verification of the emplotted story was considered in Angie’s case. As said before, some participants had discussed sensitive issues relating to partners such as abuse and suicide, which may have complicated returning the story to them for verification. However, Angie’s story did not pose such issues and it was returned to her by email for her to consider. Her response can be seen in Appendix Q.

7.3 Biographical disruption in the narratives

All of the twelve narratives, except that of Participant 11, Elizabeth, displayed the features of the concept of ‘biographical disruption’ (Bury, 1982). This concept, originally proposed by Bury, is characterised by commonly taken-for-granted behaviours being compromised, leading to the self-narrative being reconstructed and a response invoked in order to address the new-found situation (Bury, 1982).
Elizabeth married her husband after he had his ABI, thus accepting any compromised behaviours throughout their relationship.

7.4 Narrative analysis of the life stories: Two selected cases

As described above, the task of the analyst was to restructure, make sense of and reorder the data to produce a coherent story, taking care to re-present the participant’s story from their personal perspective. This is indicative of the narrative mode of cognition with the aim of exposing the narrative reasoning (Polkinghorne, 1995b). Twelve stories were constructed in this way. Each of the twelve participants recounted rich descriptions, except one. All twelve have the potential utility of representing the experience perspective of either living as the person who has the ABI or living with the person who has an ABI (a significant other). Two are presented here: one participant with an ABI; one participant who has a significant other in their life with an ABI. The remaining narrative analyses can be found in Appendix R. Pseudonyms have substituted real names and places.

Further to this, Bruce’s narrative was selected as an example, as a person with an ABI who could not offer a rich description of his narrative from a one-to-one verbal interview, due to his cognitive limitations. However, his narrative is an example of what can be achieved with the aid of a prompt tool, in this case photography. Doug’s narrative was selected as a clear example of a man who rejected the carer identity following the biographical disruption of his wife who had an ABI: his primary identity remains as a husband.

7.4.1 Narrative analysis of a life story from an individual with an ABI: Bruce

Bruce was a man in his early forties who had been the victim of an assault in the line of his work in the police approximately four years previously. He held no memory of his life before the brain injury and relied on his family members to give details of life before injury.

“It became evident early in the interview that he wasn’t a suitable participant to tell his life story. I was cross that the project worker (who passed the information sheet to him) hadn’t taken more care with this and I had come such a long way to interview him. I wondered if she had been prompted to refer him as his situation was so tragic or that her charity had been of such good help to him.”
This is an early reflexive diary entry following Interview 1 with Bruce. His conversation was very slow. He failed to elaborate on the few facts he was able to offer. It seemed unlikely that he had a story to tell. However, on completion of the three interviews it became a clear example of the strength of the photo-elicitation technique as a prompt to eliciting the personal narrative. The narrative analysis of his story is presented here. The story is presented with a flatness and lack of elaboration, reflecting the manner in which it was elicited, due to his cognitive deficits.

### 7.4.1.1 Bruce’s story

Bruce grew up in a family, the third of four children. He enjoyed outdoor activities, such as walking and mountaineering. He joined the police force. He married and moved to the country. They settled into a beautiful, large period home with extensive gardens, in a remote yet beautiful location, close to a small hamlet. It was about ten miles from the nearest town. Bruce was in his late thirties when he and his wife had a young son, Finn. When Finn was about a year old Bruce was assaulted at work and he retired.

This is all Bruce knows of his life before biographical disruption. After the accident, his family members told him stories of what he was like growing up but it had no meaning to him. The assault caused a brain injury, which resulted in Bruce living with significant cognitive impairments, including long term and short term memory deficits and flat affect, or a reduced ability to feel and express emotions. His mobility was affected in that he found he had balance problems and he required the help of a walking stick for mobilising around the house and garden. He experienced that it was extremely difficult to be in a busy or noisy environment, due to sensory hypersensitivity: auditory stimulation made him want to withdraw from situations and sometimes the visual stimulation of being a passenger in a car caused him to have blackouts. From this perspective, living in a remote and peaceful rural location suited Bruce. He found he could withdraw to his house and garden if he did not feel up to being involved in situations. The location suited their needs on the whole. However the remoteness, with no public transport service presented additional issues. He had lost his ability to drive and taxis were very expensive, so he was dependent on his wife and neighbours for lifts. This left an impact on his marital relationship as it meant that his wife was now the sole family driver and was not
something Bruce was used to. He found that he no longer wanted to take part in social situations and so of course he and his wife withdrew from these too. He found that he was most comfortable in his own space at home and keeping within these boundaries primarily. Although he accompanied Finn in the car to school, having closer contact with other children was over-stimulating and visiting such as a restaurant at very quiet times was the only option open to him.

Bruce’s wife was self employed and her work took her away from home at times meaning it left Bruce and Finn at home with support needs. The local childcare was very expensive and of course additional needs were required for Bruce to manage too. The family decided that the easiest way to solve the problem was to employ an au pair and Bruce’s niece took on this role. Bruce was essentially independent in his self-care tasks but some days were harder to achieve this than others. Finn began to grow into a well-mannered little boy who enjoyed the outdoors.

One of the main impacts of the brain injury on Bruce was the effect it had on his self-worth. He struggled with this for sometime and it was his involvement with a ‘not-for-profit rehabilitation, training and care service’ that made it easier, along with the support of his family. The organisation suggested that he take up gardening as a pastime, being ideally placed with a large garden in the countryside.

They arranged for some other people to come to his garden and join Bruce with this, as social contact and a way in which Bruce could see that he was helping someone else. Even though Bruce had flat affect he had a strong-held belief that it was
important to help people, similar to his professional background in the police force and helping the community. Additionally Bruce had the satisfaction of knowing that any excess produce went off to a community group that did not have access to much fresh fruit and vegetables. This helped build Bruce’s self-worth. Some tasks in the garden were too difficult for Bruce due to his physical limitations and they suggested raised beds (Bruce: photo1) and arranged for a member of a community group to come along and help with the heavy work.

Bruce is very engaged with his gardening today. His wife suggested they erect a large poly-tunnel so as the activity could be extended into the colder months and now he grows salad vegetables inside. He has a large crop of tomatoes and has a sense of purpose in his responsibility of being needed to water them daily or they will die (Bruce: photo2).

Finn is able to come into the garden and help a little and Bruce takes extra care with growing such as a pumpkin for Finn to have at Halloween (Bruce: photo3). Bruce is pleased to be able to do this, as one of the things he misses in his father role is to be able to do other things with Finn such as play football.
His wife likes to have flowers in the house and Bruce takes in his home-grown sweet peas and they are much cheaper than shop-bought flowers. Bruce will take in fresh vegetables from his garden for the family meals and occasionally he will try and make soup with his own produce (Bruce: photo4). He requires some assistance from his niece to do this but he does all he can. He is no longer able to follow a recipe for cooking but with a dish such as soup it is not essential and the family are appreciative of his efforts. One of the things he gets from gardening is the satisfaction of being the instigator of the process of planting the seeds right through to the meal at the family table. Again, he sees it as important as being able to help and he views it as progress in himself.
Another element of gardening has been the fun aspect of leek growing. A friend comes and takes his leeks to an annual competition for prizes for the biggest leek. Bruce has no interest in attending the show and is unable to use comparison from memory as to whether his leeks are large enough, but he appreciates the competition element and the male camaraderie and friendly rivalry between them.

The organisation also introduced him to oil painting and he was part of an art group for a while in a nearby town. He has made progress with this hobby too (Bruce: photo5) and is now quite good at painting and although he can only concentrate for about fifteen minutes at a time he loves engaging with the process and is satisfied in producing something that he can pass on to family members. He paints from photographs and always landscapes, though he cannot always remember where the photographs were taken.

Bruce has learnt to reduce the problem of sensory hyper-sensitivity somewhat, for example by using headphones in the house and avoiding busy places. He uses his mobile phone diary as a prompt for things he needs to do. He watches some television, for example current affairs, as he likes to be aware of what is happening in the world. If he watches a film his wife often reminds him that he's seen it before but he has no recall of this.

He continues to have physiotherapy for maintenance and prevention of further physical impairments. The gardening is also good exercise for him and encourages...
his mobility. He continues to have very reduced feeling and expression of emotion but he considers himself very lucky that he has a wife who has been prepared to stick with him. He tries to do the things that he can do to try and move forward with his life and sees progress and helping as two important aspects of life.

7.4.2 Narrative analysis of a life story of an individual who has a significant other with an ABI: Doug

Doug was a man whose wife had experienced a brain injury some twelve years earlier, them having previously been an active and outgoing couple. He had been an active leader in a local head injury charity.

“Last week’s interview had gone so well, with a flow of information, with Doug in sound spirits that I had no reason to think that the final interview would be any different. However, when I arrived he said that he had not been expecting me ‘til the next day and he was tired as his wife hadn’t slept until 4.30 a.m. He said that this unpredictability was typical of his life but he still wanted to proceed. I had predicted an upbeat sort of interview (after last week’s), talking about how he had overcome many barriers long term, but this day to day talk about coping was quite downbeat and revealing in terms of the psychological stress he was under and the impact on his wellbeing.”

This reflexive diary entry at the beginning of Interview 3 with Doug exemplified a potential dissonance between how individuals present their story when prepared and unprepared when daily living issues are disrupted. Any narrative that is elicited could easily be replaced by an alternative in differing circumstances. The narrative analysis of his story is presented here. The story is recounted with the elaboration and emotion with which it was recounted.

7.4.2.1 Doug’s story

Doug is in his seventies and lives with his wife in a small remote rural village. His wife, Rose, had a brain injury as a result of negligence in hospital. They moved to the area to access a good brain injury service to meet Rose’s health and rehabilitation needs.

Doug was born and grew up in the Midlands. His working career began in the men’s clothes retail business and he moved with his work to live in the South of England for some time. It was when he decided to move back to the Midlands that he first met his wife. This occurred as a coincidence in that they both travelled from London
to his hometown on the same day, with Rose travelling to meet one of Doug’s family. They identified with each other from the very beginning and became not only romantic partners but the best of friends too.

It was whilst seeking career advice that he was steered from being a client to actually working in the Job Centre service. He took on an administrative role, which eventually proved very successful. He gained status through a number of promotions, working his way to regional responsibilities of leadership, finance and people management. His wife worked in the same service and they were notable in their relationship in that they spent lunchtimes together, holding hands, which displayed the strength of their marital relationship to their work colleagues.

Their leisure time was also predominantly spent together, which Doug saw as a defining factor of their friendship and closeness. In his early mid-life Doug began to focus on his health and fitness, having realised one day how unfit he was and involved Rose in this too. They became keen runners and both took a developmental and leadership volunteer role in a local running club. Doug focused on competitive long distance running and encouraged Rose as well. Other restorative activities involved camping and caravanning in the UK and Europe, where they enjoyed the variety of travel and local culture and established a social network that they would meet regularly. As his career progressed circumstances led to Doug becoming self-employed and he took up courses in financial management and began helping small businesses manage their own finances.

The holiday trips abroad continued to be important in their leisure time and it was following one trip to Europe that Rose, who had been healthy and fit to this point, required emergency hospital admission due to becoming unwell. It took some time to diagnose the cause of her illness and there were severe complications in stabilising her medically. This was questioned by Doug and other family members. Healthcare fell well below the expected standard and Doug spent most of his waking hours supporting Rose in a hospital which was short staffed and patients’ basic needs often not attended to. Some years later this was acknowledged in a public enquiry into the standards of care in this particular healthcare Trust. Whilst Rose was in the hospital’s high dependency unit one evening she had a cardiac arrest and subsequently acquired significant brain damage. To this day Doug carries guilt and regret in trusting that Rose was being supported by nursing staff in the unit, that night whilst he went home to rest. The medical advice given was that Rose would
not recover and it would be kinder to withdraw treatment interventions to allow a swifter death. Doug remained at her side, comforting her and it was him that detected some small signs of recovery. The medical staff dismissed this but he remained persistent and optimistic until they acknowledged this themselves and treatment was re-administered that led to Rose having a degree of recovery.

A rehabilitation programme was introduced as a result of Rose’s signs of recovery, but again this fell below expected levels of healthcare and administration of basic needs. There were numerous incidences of neglect, such as being left requiring toileting assistance and food being left untouched, as Rose could not reach or feed herself if he was not there to help. Physiotherapy intervention was productive and improvements were made cognitively and physically, though psychologically Rose deteriorated. Intervention involved purely medication to address the subsequent mental health issues, which they considered wholly inadequate.

Discharge home brought additional problems, as the house was not adapted to Rose’s physical disability needs. The 24-hour care, that she had been assessed as needing by the social worker, did not materialise. Housing adaptations in their particular urban area seemed unobtainable, with what seemed an incredible notion of having to wait to be put on a waiting list! Doug relied on the assistance of friends, as statutory services were not forthcoming. Transport to hospital day services for rehabilitation was unsuitable and worsened Rose’s health status too.

He found the reaction of friends and family to their situation difficult to understand: some became closer and provided invaluable support whilst some displayed a complete rejection. People they had previously classed as close friends made it clear they would not be visiting in hospital and friendships waned. Some close family members also refused to visit in hospital. This latter reaction took Doug by surprise, as he and Rose were still the same people that they had always been, just now in difficult circumstances and in need of help. During this very difficult time of coping they were made aware that some areas of the UK had much better brain injury services, through a relative living about 200 miles away in a rural area. They made an immediate decision to move to the distant rural area, leaving behind long-established friends, but balanced by the intensity of the need for better support and rehabilitation for Rose.
This move proved hugely successful, as the multi-professional healthcare services were immediately responsive and individualised to Rose’s needs and housing adaptations were prompt too in this remote rural location. Knowing that there was always someone from the brain injury service to help at the end of a telephone was reassuring. Occupational therapy to encourage independent living was well received by Doug and Rose and the contact with the hospital consultant excellent. Doug views this sporadic shortfall in services nationally as limiting progress and activity for many people with acquired brain injury. A financial compensation package for negligent medical care followed, allowing them to buy an adapted property and 24-hour support, but he acknowledges that many people with brain injury have to rely on statutory services, often lacking and leaving families unable to cope.

Doug and Rose have always coped with their situation by continuing as far as possible with normal activities. Rose remains Doug’s best friend and closest companion. Following her biographical disruption she made cognitive and physical progress to walk with minimal support. Although they lost their leisure time pursuit of caravanning with friends they were able to re-establish going abroad, by finding a small, adapted hotel run by very accommodating English hoteliers. Their emotional closeness has been maintained throughout and for their 40th wedding anniversary they went on a cruise and Doug made his marital and emotional commitment clear by asking Rose to marry him again. They renewed their vows on board ship in what was a surprise service for Rose, Doug even going ashore alone to buy Rose a special outfit for the event.

A setback emerged in Rose’s health status on their return and even today, some year’s later, her recovery is less marked than following her first episode of ill health and brain injury. There is an unpredictability in Rose’s health status that contributes to the challenges of living with an acquired brain injury, in terms of planning where to go, what to do and when people can visit. However, Rose does not identify herself as a disabled person, even though she has cognitive and physical disabilities. She prefers not to holiday in large hotels that specifically cater for people with disabilities as she finds this distressing, though is sympathetic. Instead she prefers venues that are accessible for all and visited by all, especially overseas.

Doug and Rose used some of the financial compensation from the medical negligence to buy an already adapted bungalow. They try to live as man and wife but Doug is responsible for managing a 24-hour a day, seven-days a week
rehabilitation and support package for Rose. Doug has the skills for leadership, people and financial management, from his previous career role which has helped tailor a very specific rehabilitation package for Rose’s optimum recovery. This is underpinned by a belief that individuals can develop and grow under the right circumstances.

However, a dilemma does arise. He finds himself in the situation of people management during the day, yet the same staff seeing him in his pyjamas at night and entering his shared bedroom to support Rose if she needs assistance during the night. Some of the staff are understanding but not all and it can undermine what he is trying to achieve in terms of a comprehensive, well run rehabilitation package for Rose. He feels the need to be responsive in a professional manner at all times, yet he feels intense pressure and stress in both roles. He and Rose have affection for a number of the staff who have been with them since arriving in the area and count them as friends, but personnel issues do arise. Currently Rose’s niece assists with the managerial issues on a part-time basis and they have established a routine of enabling staff to take responsibility for key areas of Rose’s needs to try and manifest the smooth day to day running of issues. A limiting factor of the rural environment is the fact that support staff travel long distances to work and it restricts the flexibility of working hours.

Doug and Rose’s relationship continues to reflect the friendship and emotional closeness of their long marriage. They continue to engage in activities together, such as shopping trips and visits out for lunch or coffee as well as holidays. Despite this Doug sees himself as having lost much of the role as husband, possibly due to the intrusion on privacy that Rose’s care package brings with it (Doug: photo1).
So much of his time is absorbed in meeting Rose’s health and wellbeing needs in managing her rehabilitation package well that much of the intimacy is lost, which he mourns and puts an increasing strain on him. Rose maintains some of her role as homemaker and sees cooking and cleaning as part of this. Doug has incorporated this into her rehabilitation programme, by encouraging her to wipe a few pots after the meal and make small contributions to home care, rather than the tasks all being done by the care staff.

It has been made clear to Doug that in order to maintain his own health and wellbeing he needs to spend some time outside of the home with restorative activities. The constant pressure of emotional stress and managing Rose’s care staff has an impact on both his psychological and physical health. He still identifies himself as a fit individual but acknowledges the impact of his situation on his own health. However, it is not easy to spend time outside of the home to counteract this, as their social circle is limited and their location remote, in addition to Rose being his closest companion for many years. Their closeness brings a dilemma in that he wants to be there as emotional support and companionship for Rose, whilst at the same time it puts him under great strain. He does not feel able to make the case for his own health and well being with Rose in case it causes her anxiety. This extends to his reluctance to make a case for himself to sleep alone to get a restful sleep: he and Rose have always slept together, yet now she requires help from the paid carers in the night and this wakes Doug and prevents him from resting. Also, he knows the nuances of optimum intervention through rehabilitation with Rose like no other and sees it as essential that this is promoted and sometimes individual staff members are not fully aware. He still recalls the night he left Rose’s care in the hands of nursing staff and she experienced a cardiac arrest that led to the brain damage. The strong need to protect Rose is evident. All in all, this leads to him feeling trapped in the situation and seeing no resolution at times.

Doug has always been protective of Rose since her brain injury, possibly spurred on by that occasion when he left her to the trust of healthcare professionals and the brain injury occurred, changing their lives. This has been exacerbated by a recent hospital admission when he had to intervene with a nurse administering incorrect medication through not reading Rose’s case notes. The majority of the brain injury service in the rural area has been excellent, but he remains dismayed when senior healthcare staff deliver damning prognoses when he feels they should be
motivating. He values shared decision-making with healthcare staff and draws on their expertise to validate rehabilitation choices they make for Rose.

Over-archingly, Doug’s approach is one of looking for growth and development with optimism for people with acquired brain injury, including Rose. He is quick to dismiss a vocabulary of ‘care’ around Rose, instead promoting ‘rehabilitation’. They engage in normal activities and she is his life-long companion and best friend. They still look towards being able to travel abroad at some point in the future, even though progress is needed in the rehabilitation in order to make this happen. He expresses his admiration for Rose and acknowledges her resilience in the face of continued ill health.

The property they live in is very remote, though suitably adapted. As they are a couple who have always enjoyed socialising and visiting places they now have to think carefully how far they go away from home as places may not have toileting facilities accessible for a wheelchair. They would prefer to move to a local town but suitably adapted properties are few and far between and they would be in competition with other buyers if something did come on to the housing market and have to sell their own property first. Established friends have been left behind in the Midlands and there seems to be few opportunities to make new ones. The local pub is one of the few community meeting places and Doug sees this as a valuable place to seek out male company (Doug: photo2), which he very much values due to so much time spent with female care workers.
However, the type of previous friendships they had in couple relationships is not available here. It is more difficult to establish friendships where they are invited to visit people’s homes and socialise, which is an activity they were familiar with before the biographical disruption. Doug feels the need to spend some time in male company away from the home, with the home being continually occupied with female support staff. However, there is a dilemma in that the pub is only busy in the evenings when he feels the need to be at home for Rose to settle her down to sleep, as they share a bedroom as always. Rose can become anxious if he is not around, which can prompt seizures and subsequently they both become distressed. He has an established group of friends in the pub with whom he has a share in a racehorse, which gives them a common interest and leisure activity of visiting the stables (Doug: photo3) and hoping to visit the races as owners in the future.

Disappointment is expressed by Doug at the distancing of some family members, despite them living close by. Relatives that were once close and with whom they feel an emotional connection visit infrequently, if at all and there is not an opportunity for Doug and Rose to visit due to houses lacking appropriate environmental design for wheelchair access, even though many public spaces are accessible these days. They no longer receive invitations to people’s houses.
possibly due to it no longer being convenient. This adds to the disappointment at no longer having the wide social network they previously enjoyed. This leaves a tinge of regret but he tries to put this issue aside and move forward. They are fortunate in one respect that financial compensation followed the proven negligence in Rose’s brain injury, allowing a full ongoing rehabilitation package with 24-hour assistance. But in no way does this compensate psychologically, emotionally and physically for Doug and Rose’s situation.

Doug has not only drawn on his financial and management experience in organising Rose’s rehabilitation package but also put these skills to good use in setting up a local branch of a brain injury charity in the nearby town. His approach has been to empower the members with brain injury to take on leadership roles for themselves and contribute to their self-development, which has brought him a sense of joy and satisfaction. This again reflects his approach of promoting growth and development of individuals with a brain injury and acknowledging both their needs and their potential contribution to society, just as he promotes this with Rose. He has been instrumental in organising an annual weekend for people with brain injuries and their families, for some years now at an outdoor activity centre. The weekend presents challenges to participants and promotes confidence and self-esteem, education around brain injury issues and fun. Often participants take part in activities they haven’t attempted for years and express how much it improves their confidence. He sees this as another opportunity for people with brain injury to develop and improve, with the appropriate kind of assistance and appears to hold an optimistic view of the future for the people with brain injury he comes into contact with.

The potential utility of the two examples offered above (and those of the other participants) lies in a both offering a greater understanding of the lived experience of the impact of an ABI as well as offering an interconnectedness between those that speak them and those that hear them (Frank, 2013).

7.5 Chapter summary

This chapter begins Act III of the thesis, presented as a three-act story, in that it presents how the researcher attempted to resolve an understanding of the issues for a disruption to narrative, occupation and identity due to ABI. Presented is an analysis relating to the narrative components of the data, by way of offering selected
examples from the process of narrative analysis (representing the narrative mode of cognition). As data produced in narrative research does not lend itself to distinct results and analysis this was considered the appropriate way forward. Having considered the narrative analysis of the data, Chapter 8 will now consider the analysis of narrative (representing the paradigmatic mode of cognition) (Polkinghorne, 1995b).
Chapter 8  The stories analysed: Narrative tone, typologies and analysis of narrative aspects

8.1 Introduction to the chapter

R Do you get any sort of erm, internal reward from being able to contribute to that or…?
B …to, it’s a good thing to do.
R Uuhh, uuhh.
B I, I don’t have huge emotions about any things…
R Yeah.
B …but I know it’s a good thing.

This is a quote from the conversation between participant Bruce (B) and the researcher (R) in the participant’s final narrative interview. Bruce had been describing a number of different occupations he engaged in, such as growing vegetables for the local community. The researcher was probing for his motivation to engage in the occupation. The response was indicative of the overall tone of Bruce’s interview, neither optimistic nor pessimistic (Mcadams, 1993) but neutral, possibly due to the nature of Bruce’s ABI.

This chapter continues the resolution of the plot of the thesis and presents the narrative tone and the plot typologies of the twelve participants’ stories. The analysis of narrative is presented (Polkinghorne, 1995b) for two participants, selected due to being representative of the lived experience of one individual with ABI and one significant other.

8.2 Narrative tone and typologies in the overall narratives

Narrative analysis theory suggests a number of varying ways in which analysis of narrative can be undertaken. Logically derived plot typologies arose from the deep immersion in the data by the researcher whilst acting as analyst (Polkinghorne, 1995b). This is of particular interest later in the study, when the traditionally perceived ways of viewing disability and its subsequent rehabilitation will be discussed. Specifically the analyses offered here relate to the following issues: narrative tone (McAdams, 1993); typologies of illness narratives (Frank, 1995); progression / regression / stability (Gergen & Gergen, 1986); literary genres (Frye, 1957). The results are presented in Table 2.
Table 2: Narrative tone and typologies in overall narratives

<table>
<thead>
<tr>
<th>Participant (Pseudonym)</th>
<th>Narrative tone</th>
<th>Frank’s typologies of restitution / chaos / quest</th>
<th>Gergens’ progressive / regressive / stable (overall)</th>
<th>Frye’s tragedy / comedy / romance / irony</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rachel (SO)</td>
<td>Pessimistic</td>
<td>Chaos</td>
<td>Regressive</td>
<td>Romantic tragedy</td>
</tr>
<tr>
<td>Sam (ABI)</td>
<td>Optimistic</td>
<td>Quest</td>
<td>Mixed</td>
<td>Tragedy</td>
</tr>
<tr>
<td>Angie (ABI)</td>
<td>Pessimistic</td>
<td>Chaos</td>
<td>Stable</td>
<td>Tragedy</td>
</tr>
<tr>
<td>Bruce (ABI)</td>
<td>Neutral</td>
<td>Chaos</td>
<td>Progressive</td>
<td>Tragedy</td>
</tr>
<tr>
<td>Susan (ABI)</td>
<td>Optimistic</td>
<td>Quest</td>
<td>Progressive</td>
<td>Tragedy</td>
</tr>
<tr>
<td>Hilary (ABI)</td>
<td>Optimistic</td>
<td>Chaos *</td>
<td>Progressive</td>
<td>Ironic tragedy</td>
</tr>
<tr>
<td>Helen (SO)</td>
<td>Mixed</td>
<td>Quest</td>
<td>Mixed</td>
<td>Romantic tragedy</td>
</tr>
<tr>
<td>Christopher (ABI)</td>
<td>Optimistic</td>
<td>Quest</td>
<td>Progressive</td>
<td>Tragedy</td>
</tr>
<tr>
<td>Doug (SO)</td>
<td>Optimistic</td>
<td>Chaos</td>
<td>Mixed</td>
<td>Romantic tragedy</td>
</tr>
<tr>
<td>Elizabeth (SO)</td>
<td>Optimistic</td>
<td>Restitution</td>
<td>Progressive</td>
<td>Romance</td>
</tr>
<tr>
<td>Diana (SO)</td>
<td>Optimistic</td>
<td>Quest</td>
<td>Stable</td>
<td>Ironic tragedy</td>
</tr>
<tr>
<td>Rita (SO)</td>
<td>Optimistic</td>
<td>Quest / chaos</td>
<td>Progressive</td>
<td>Romantic tragedy</td>
</tr>
</tbody>
</table>

KEY:

*chaos in terms of own cognitive limitations (cognitive chaos) making other types not possible.

SO – significant other in the life of someone with an ABI
ABI – person with an ABI

8.2.1 Optimistic and pessimistic narrative tone in the narratives

The narratives were analysed for the overall narrative tone, be it optimistic or pessimistic (McAdams, 1993). An optimistic tone was assigned to the narrative where the story continued to show optimism, even in the face of bad things occurring. Alternatively, a pessimistic tone was assigned where there was an overall negativity, in the face of both good and bad occurrences (McAdams, 1993; Crossley, 2000). During the analysis it did not seem possible to assign either option
to one participant: Bruce (ABI: P4). Bruce had awareness that he no was longer able to express feeling due to the nature of his specific brain injury and he did produce a narrative that appeared neutral and factual. His narrative also had brevity and lacked detail, again due to nature of his cognitive deficit of memory and his fatigue. This exception to McAdams’s binary idea may lie in its theoretical underpinnings. McAdams suggests that narrative tone is dependent on the form of attachment relationships formed during the childhood stage of development: secure attachments leading to an optimistic tone and insecure attachments leading to a pessimistic tone (McAdams, 1993). Bruce acquired his brain injury around the age of 40 and it left him with cognitive deficits resulting in no memory of his life events pre-injury. If he wished to know about his childhood experiences he had to ask family members about them, which would perhaps preclude him from holding a sense of the secure or insecure attachments.

So what type of narrative tone did the other eleven participant stories display and was it easy to assign either pessimistic or optimistic tone these stories, supporting McAdams’s theory? Two of the participant narratives appeared to have overall pessimistic narrative tone: Rachel (SO: P1) and Angie (ABI: P3). This may align to McAdams’s attachment theory ideas in that Rachel is very open about a turbulent and difficult childhood relationship (and continuing difficult relationship) with her father. Angie’s situation differs in that she reached almost eighteen years of age before acquiring her ABI, brought up in a positive family environment. However, she displayed behavioural issues once she acquired her brain injury, which she knows affected her relationship with her mother. The simple binary choice of optimistic and pessimistic tone was hard to make for participant Helen (SO: P7). Her story included talking about not having the relationship with her father that she had hoped for, in that it lacked closeness. But now she has a degree of resolution to this in that she is proud that he has acknowledged her tenacity in coping with a family under stressful circumstances.

Of the eight remaining stories four were of individuals with ABI and four were significant others. All eight appeared to display an overall optimistic narrative tone, despite having experienced biographical disruption. McAdams’s secure attachment theory may be supported by this in that only one of the eight, Sam (ABI: P2) discussed a parental relationship negatively, although in compensation he had an extremely strong attachment to his other parent and was still influenced by his positive relationship with his father even though he died many years ago.
Interestingly Rita (SO: P12) was brought up in a non-western collectivist culture where children were commonly not brought up by their parents. She discusses forming a strong attachment to God as a child, having been brought up in a Catholic boarding school and her life was still guided by God at the time of the interviews. So although Sam and Rita did not form secure attachments with their mothers, they did have opportunities to form secure attachments during their developmental years to influence an optimistic narrative tone (McAdams, 1993).

So how does this ability to remain optimistic despite biographical disruption sit with traditional depictions of ABI? When one considers the cultural transmission of imagery through media such as folklore and fairy tales in the western world, those who have exhibited negative behaviours and attributes, like envy, gluttony, vanity, lust and greed, are the ones who are rewarded with lives that result in punishment and tragedy (McAdams, 1993; Cashdan, 1999). ABI stories typically include some form of tragedy, thus there can be a cultural expectation of negativity around stories of lives impacted by ABI. From a social constructionist perspective the symbolism of reduced opportunities in life and an accompanying impact on social status could further support an expected pessimistic storyline (Berger & Luckmann, 1966). Signs of physical or mental disorder typically lead to stigmatisation (Goffman, 1963). Any resulting negative impact on personal and social identity would further compound this display of optimistic narrative tone.

A number of contributing factors may go some way to explaining this. Firstly, McAdam’s attachment theory may hold significant weight in that the secure attachments experienced in the developmental years strongly influenced the narrative tone. Secondly, significant others in the study who displayed optimistic narrative tone may be heavily influenced by the positive aspects of caring and the opportunity it has offered them in life, such as bringing families closer together (de Arroyabe, Alvete, Las Hayas & Zubizarreta, 2013; Las Hayas, de Arroyabe & Calvete, 2014). The co-occurrence of positive and negative emotions in any one day is also common (Folkman & Moskovitz, 2000) and considering that the narrative was a construction of self in front of the researcher these participants may have had a tendency to emphasise the positive elements. Also, biographical disruption can commonly cause a re-evaluation of life’s priorities and values, which may have gone part-way to accounting for this positivity in the face of adversity (Conneeley, 2002; Cantor et al., 2005).
8.2.2 Typologies of quest, chaos and restitution in the narratives

Returning to Table 2 and Frank’s typologies of quest, chaos and restitution narratives, what might be concluded from the typologies assigned to the narratives of this study? And did the twelve participant narratives fit neatly into Frank’s categorisation? Considering Elizabeth (SO: P10), her narrative was the only one that appeared to have elements of Frank’s restitution narrative. Her’s was a story of having married a man who already had an ABI, which she was fully aware of and its symptoms. This type of narrative typically is one of recovery from health and getting well again. However, as far as Elizabeth was concerned her husband as a person was very much foregrounded in the narrative and health issues downplayed as part of daily life. Thus although it did not strictly follow Frank’s (1995) description of recovery from health and getting well, neither did it fit with a quest or chaos typology.

The chaos narrative espouses a life sent off the rails with diagnostic uncertainty. Frank (1995) also suggests a lack of temporal progression with such typologies, that they are anti-narrative. However, elements of a chaos narrative were seen in six of the participants’ transcripts, though most demonstrated some temporal progression. For one, Hilary (ABI; P6) the elements of chaos were compounded by attempting to tell a narrative with severe cognitive impairment, making it almost impossible to move into another typology with her story.

The quest narrative exhibits the domains of what Frank calls ‘memoir, manifesto and auto-mythology’ (2013, p.119). This equates to recounted memories, a call for change and a reinvention of self. Six participant narratives demonstrated this. For example, Susan (ABI: P5) gave a strong account of her past illness situation, called for greater individualised care in hospital and was looking for a new challenge having given up her nurse role. Rita (SO: P12) recounted her story in detail, campaigned for better access to health and social services and saw herself as ‘The Good Samaritan’ in that she had been called to do God’s work.

But did all of the categorisations have goodness of fit? By no means, and indeed Rita’s narrative also exhibited elements of chaos and not knowing where to turn for help. Indeed the most recently proposed typologies suggest an illness experience narrative potentially containing all three typologies, further adding a trickster narrative and additional typologies may need to be generated (Frank, 2010; Frank,
2013). It would seem that elements of Frank’s typologies were observed in this study’s participant narratives, though it would be hard to argue for a neat categorisation.

Table 2 also categorised each narrative as either progressive, stable or regressive overall (Gergen & Gergen, 1986). However, being able to assign one or other of these categories was difficult. Some were clearly progressive, where participants were working towards goals in life, such as Christopher (ABI: P8), who was on a quest to establish a neuro-culture that was not there for him when he needed it. Sam’s narrative was complex with respect to this (ABI: P2). He acquired his brain injury nine years previously and lived through a difficult period for some time afterwards (a time of regression). However, life progressed when his tumour, which caused the injury, returned. It would be difficult to firmly assign a regressive label to this episode of the narrative as he was engaging in occupations that satisfied him and he was making decisions about how to make the most of his time left.

Similarly it was difficult to categorise Helen’s narrative (SO: P7). An overall theme of stability and coping, following a regressive episode at the time of the ABI was observed in the narrative, yet the photographs starkly revealed her husband occasionally contemplating suicide, which was always a backdrop to the day-to-day life she lived. It can be concluded that applying this type of categorisation to the narrative appears less useful, possibly compounded by people in such situations potentially having a co-occurrence of positive and negative emotions in any one day (Folkman & Moskovitz, 2000).

### 8.2.3 Literary genres of the narratives

Frye’s theory of literary genres (1957) was considered with the twelve narratives: tragedy, comedy, romance or irony. The genres were much clearer then the typologies of Frank’s and Gergen & Gergen’s. Even though the narratives were not event-centred and were experience-centred instead, the event of acquiring the brain injury was at the crux of each, bar one. In literary genre types this would indicate some form of tragic story. The exception was Elizabeth (SO: P10), who married her husband knowing about his ABI and accepted this as part of who he was, dealing with any issues arising from the symptoms: this was more of a romantic story form. Elements of romance were layered over four of the other narratives, in all cases significant others, where it was their partner who had an ABI. Two of the other
participants, Hilary (ABI: P6) and Diana (SO: P11), displayed a layer of irony to their narrative, in that they utilised humour in an ironic manner to relay the story in parts. The utility of applying such literary genres to the participant narratives is with reservation and of interest from a narrative theoretical perspective only. One utility of the narratives is in dispelling commonly held negative stereotypes about living with ABI and utilising them to help people construct new imagined futures if in similar situations: drawing on the emotive discourse of *tragedy* might have the opposite effect.

8.3 Analysis of narrative

Further analysis of the data was undertaken to expose the paradigmatic reasoning in the narratives: analysis of narrative. Analysis of narrative can be achieved in several ways, such as seeking conceptualisations or themes in the data (Polkinghorne, 1995b). Analysis performed via the narrative psychology approach adopted in this study is presented here, the details of which are offered in Section 6.7.3 of Chapter 6. Twelve accounts were constructed in this way. Two are presented here: one participant with an ABI; one participant who has a significant other in their life with an ABI. The remaining analyses of narrative can be found in Appendix S. Pseudonyms have replaced real names.

Further to this, Christopher’s narrative was selected as an example of one that stood out from the twelve in that it more typically followed the canonical storyline: a protagonist who faces adversity, overcoming it to find some form of resolution (McAdams 1993; Cashdan, 1999). Rita’s narrative was selected by way of it containing a wealth of considerations and complexities: it defies neat categorisation into Frank’s typologies, with elements of both quest and chaos (Frank, 1995); she draws on a well-known story depiction to frame her narrative (in this case a biblical one) and despite significant biographical disruption to a hoped for romantic storyline, she remains optimistic and sees progress. No direct quotes are offered from the reflexive diary as the diary content was subsumed into the positional aspects and subsequent analysis. The interview number and line number of the transcript are offered in brackets following direct quotes.
8.3.1 Analysis of narrative of a person with ABI: Christopher

Christopher was a man in his late forties who had experienced biographical disruption due to an ABI some twenty-three years previously, following removal of a brain tumour and a subsequent stroke. He had spent many years trying to make sense of the disruption but had reached a stage of his life where he was moving forward and trying to establish a ‘neuro-culture’ that had not been there for him at the time of the onset of his ABI. Analysis of narrative differs from the narrative analysis in that in this study it is analysed from a psychological perspective, as opposed to following the plot and desired presentation of self of the narrator/participant. Here is Christopher’s story following ‘analysis of narrative’.

8.3.1.1 Positional aspects of Christopher’s narrative interview

Christopher struck me as someone who was very intelligent with huge potential in his twenties, then had those opportunities taken from him due to his ABI. He seemed to discuss little about his life before the brain injury and it became apparent that it was too painful for him to spend time dwelling on this area of his life, due to the enormity of the biographical disruption.

He also came across as very insightful and reflective. This seemed to have helped him progress with his narrative after his biographical disruption and he mentioned his self-identity and being poor but rich in so many other ways. His talking about feeling like a catalyst instead of a capitalist led me to think that his story was a ‘quest’ (Frank, 1995). He also sought opportunities to discover the meaning behind his life.

Intellectually Christopher appeared to be very high functioning and I wondered how much this had been helpful in his adjustment to biographical disruption.

8.3.1.2 Analysis of Christopher’s interview

Christopher is a forty-seven year old man and lives alone in a bungalow in a rural village. He has a partner who lives about five miles away. He finds that the quiet rural environment gives him clarity of thought, which is important for dealing with his cognitive issues.
He grew up in a supportive family and developed a love of cars and sport, especially motorsport. He decided to follow a career in engineering. On completion of his degree he was offered a number of lucrative opportunities but set his aspirations higher and undertook a PhD, with the aim of working for NASA. However, soon into his PhD he developed a brain tumour. Not long after this was removed he experienced a stroke.

Twenty-three years later he has a left sided hemi-paresis and some cognitive issues. The specificity of the cognitive changes in his parietal lobe mean that he is unable to undertake high level mathematics, which he previously required for his engineering career (Headway, 2016a). He is circumspect about his biographical disruption.

This statement is representative of how Christopher has shaped his narrative:

“I thought there’s bound to be other people with brain tumours following me and that somehow I’d fallen through a trap door and the trap door was still open and other people would fall down it following. So it became my quest to somehow at that stage, I wanted to try and close that trapdoor and try and enlighten an immensely dark place erm.. which I was experiencing at that time”

This synthesises the catastrophic reaction, which commonly occurs with neuro-trauma, a lack of neuro-capital to draw on as a resource at the time of biographical disruption (Medved & Brockmeier, 2008) and the value that can be gained in creating something that exceeds you, in the form of a legacy (Frankl, 1946).

Christopher’s narrative tone is overall an optimistic one. This could be influenced by his childhood and formative years, within a positive family environment and also as a teenager he was a highflyer, which could have served to build his confidence and self-esteem (McAdams, 1993). He was heavily engaged in sport and academic achievement, before his acquired brain injury.

It is difficult to know whether he carried an optimistic narrative tone for a significant number of years post-injury. He talks about previously being ‘in a spin’ and ‘on a roundabout’ and it is only in the last four years he seems to have managed this new state of mind and his optimistic outlook on life. He is now reflective on his life and where life may have taken him, had he not had his injury. He talks about perhaps him becoming a capitalist if he had continued on his very successful trajectory in life, whereas now he sees the altruistic benefits of being a catalyst. This motivates him
to use his engineering background to construct a website for disabled people to use as a resource for problem solving, as well as a motivation to engage with activities such as sport.

He is keen for disabled people to be seen as able and for society to be inclusive (Leonard Cheshire Organisation, 2010). He gives time to charities to help facilitate this, for example the National Parks Authority and helping them trial outdoor wheelchairs for rambling, demonstrating a degree of altruism (Frankl, 2004). He sees many sports putting disabled people on the sideline, but has found his niche in racing sailboats, in that it has a highly competitive arm for disabled people and has been inspired by other participants. He would like to take this activity to the highest competitive level but lacks the financial resources to do this.

Optimism is reflected where he carries a satisfaction at his own diligence in terms of self-rehabilitation, “I did my best but you can’t fight a dead area of your brain to such an extent. I’ve got no regrets. I did the best” (1/11).

The area of his life story that is less optimistic relates to his finances and the way he sees disabled people treated disrespectfully as benefit claimants, with limited work opportunities (McAdams, 1993). He feels that disabled people are used as conduits for transferring money to uphold the benefits system. He is resentful of employers who take money to engage disabled people on work training schemes, then disregard them when the scheme finishes.

Progression is very much evident in Christopher’s narrative of his early years, through childhood and adolescence (Gergen & Gergen, 1986). Christopher’s early years were within a supportive family environment, “My family is quite a close family” (3c/4), which may explain his optimistic narrative tone (McAdams, 1993). He recalls his teenage years as happy times, “I had me Volkswagen Beetle and I was, I was all I had that and me windsurfing. I wouldn’t say I was made up but I was…” (2/56). Using a theory of comparison processes he is suggesting that his life situation at that time was ideal compared to others (Festinger, 1954). This is the same when he discusses his educational achievements. The progression in his narrative continues through his student life, “I loved being a student” (2/60). He took opportunities to learn through his experiences (Dewey, 1938), for example working in the US as a student:
This experience of the US, combined with his high achievements in engineering led to him undertaking a PhD with an end goal in sight, "I had aspirations to work for NASA" (2/80).

There is an occupational persistence or habituation in Christopher’s story of outdoor sporting activities (Kielhofner, 2008), “I’ve always appreciated the outdoors” (1/11); “Erm, so I was highly active, highly fit, mountain biking and everything” (1/11) and cars and engines, “I’ve been fascinated by cars” (3a/194); “I would have been a rally driver if I could have done” (3a/196). He identifies with the males in his family through this passion (Lawler, 2014):

“My Dad got me into cars and I used to go watching cars and motorbikes with my Dad and my Grandad and so we were car and motorbike daft” (2/158).

Then a major regressive episode occurred when Christopher fell unwell with a brain tumour, followed by a stroke. This was a major biographical disruption (Charmaz, 1999). Christopher draws on terminology to express the enormity of his biographical disruption, “It’s a mammoth thing. Brain injury is a mammoth thing I’ve found” (1/2), (Berger & Luckmann, 1996). He sees his life as taking on two identities, both pre and post the ABI, “this is like my second life. I had a life before brain injury and a life after” (1/2) (Gelech & Desjardins, 2010). This delineation is indicative of a catastrophic reaction to neuro-trauma (Medved & Brockmeier, 2008). At this time his future plot was unknown:

“What happened to me career wise and life wise and where I was heading was all lost. And my, my future went out of the window. Erm, in every way” (3c/8-10)

Following the biographical disruption there was, as commonly occurs post-injury, a failure to embody the new disability identity, “As I said I, in the early stages I was in a spin. Which was literally a flat spin that I couldn’t get out of” (2/24) (Medved & Brockmeier, 2008).

Much of Christopher’s discourse draws on engineering terminology and he acknowledges this:

“and it was dark days and I was in a tremendous spin, not knowing, what I used to call it, dragging my anchor. I had no… this is the engineering coming out but I had
This could be due to his strong engineering identity (Tajfel & Turner, 1979). He uses the engineering terminology to make sense of his life during a period he describes as ‘self-grief’, which could be part of a grief reaction to his biographical disruption (Carey, 2014). He described himself at times when he was not making any progress in trying to return to his pre-injury self as an:

“open loop situation. And those I know from my education, opened up systems are very bad. Er, they’re the ones that fall out of the sky” (3b/370-374).

He decided at this point to try and set up new systems that would work towards his improvement.

Whilst in hospital he was aware of his physical deficits but initially not his cognitive issues. During occupational therapy he found he was unable to describe once familiar scenarios:

“I couldn’t construct any sentence, words erm. They eventually took the picture away from me er without me having been able to describe anything … probably the first experience of the mental side of my disability” (2/212).

This illustrates a point of gaining some awareness (Headway, 2016b).

He went through a period of striving to return to the pre-injury self (Nochi, 2000), which lasted for many years. His family engaged with this too, “my Dad, as well he felt too bad for my situation that he felt he wanted, he needed to do as much, aid me as much he could” (2/210). Christopher recounts the affect this had on his parents as well as himself, “And that I was looking forward to and this is what I had to get to grips with. It’s what also, what me Mam and Dad had to get to grips with” (3c/8-10) indicating the impact on his loved ones (Heller, Levin, Mukherjee & Reis, 2006). During this striving to return to the pre-injury self, his father looked to establish a rehabilitation programme for him, as none was forthcoming from statutory services, “my Dad was the first person to re, to sort of seize, seize it. Erm, in as much as trying to stop me getting any worse” (3b/348). He talks about him and his parents having a ‘plight’. He describes his experience, “It all contributed to me realising that I’d fallen through some sort of trapdoor. I didn’t feel that I was anyway different” (1/7). The plight relates to him seeing his life as being on a journey and coming across adversity (falling through a trapdoor), to be
overcome in the typical western narrative (Cashdon, 1999). He suggests that at that point he had the same identity as pre-injury (Gelech & Dejardins, 2010).

He tried to return to an engineering role after his ABI but learnt through experience that this was not going to be possible (Dewey, 1938):

“I tried to get back into it and one of the things that I’ve always well, learnt is that you’ve got to try things. Erm, so I tried to get back…. That opened my eyes to the limitations that I have” (1/11).

Trying to return to the workforce left Christopher feeling disempowered, “I was totally abused” (1/11). This was a disillusionment of the disability works placement schemes, where he felt exploited and that there was never an intention of being employed at the end of the scheme. He describes himself as being objectified as, “a commodity” (1/11) and described the workforce employers behaviours as, “they started to almost trade with you like cards” (3a/120-122), leaving him feeling exploited and depersonalised (Marx, 1843 / Livingstone & Benson, 1995). He feels that this is compounded by the public viewpoint of disability, “And predominantly people are looked at in a kind of useless way” (3b/176), explained by the social construction of disability (Berger & Luckmann, 1966: Goffman, 1963).

Christopher displays many examples of being agentic in his narrative and declares the importance of this, “Well one of the things that I’ve kind of learnt as well is that if you’re not in, is to be in control of your own destiny” (3a/510). He gives examples of when it has not been possible to be agentic, which are clearly disempowering, “Yes they took my driving licence away from me” (1/7). This would have been especially poignant for someone with such a strong identity with cars (Tajfel & Turner, 1979), and presented him with an aspect of occupational deprivation (Whiteford, 2009). This occurred at a similar time to him looking to statutory services to offer assistance:

“we were passed down a long line of hands from one to another. But eventually that long line of hands stops and you’re back on the street and there’s no-one to pick you up and you have to find your own direction” (1/7),

again reflecting disempowerment and the dehumanising aspect of a medical model that focuses on acute care (Bradby, 2012).
Christopher displayed agency by taking forward his own rehabilitation, through having access to a private running track and using this to try and push himself within his zone of proximal engagement (Vygotsky, 1978):

“When I had an athletics track to meself I could, I didn’t feel as though I had an audience. I could do all these things I wanted to try and do and do without looking daft” (3a/1025-1027).

This also suggests that he was concerned about how he presented himself in public (Goffman, 1953), whilst he was striving to be his pre-injury self (Nochi, 2000). He reflects a hardy personality (Kobasa, 1979), when he discusses the importance of trying hard, “If you don’t’ try things then you’ll never know and you’ll never … you’ve got to put yourself out there” (1/11).

One epiphany moment in his narrative involved his identity,

“I mean I can remember there were certain milestones. And one of the biggest was erm, ear, quite early, reasonably early on because I realised that I needed, I,I,I needed to seek what I was” (3b/404).

This appears quite insightful of Christopher to demonstrate awareness of the common identity issues associated with ABI. His loss of identity (Nochi, 2000), at this point is reflected in his engineering discourse, “I used, I was aware that I was living an inverse of the life I previously led” (2/4). What enhanced this situation was not having an image of what his future identity would be, “I was in a situation where I had no comparable anything. And erm, nothing I could relate to or compare with” (2/6).

Christopher acknowledges the importance of learning through his experience and drawing on this for coping with ABI, “In a way, it’s strange to say but my life prior to the brain tumour / disability in a way prepared me for what I had in store” (1/4), (Dewey, 1938). He uses his occupational experience of engineering to justify this further, “I knew how to tackle problems and erm, do them with a degree of strategy and thought and problem solving” (2/222). He used this approach to begin to see his life differently:

“Erm, to be able to analyse something, to strip it down and rebuild it and, and do it in the right order and the right process … ultimately it’s knowledge of life I’ve acquired and sort of before I became disabled” (3b/480-492).

He declares traits that may well have supported his recovery, “My very whole family are quite diligent with you know workwise and stuff and er, we always sort of, I’ve been brought up to do me best” (2/355). He adapts his occupations and has faith in being
able to achieve, “I always told meself that I’d get there in the end, which I tend, which I do, but it, it takes me a lot longer” (3a/156-158).

He describes one epiphany moment in his life being when he read a book by Oliver Sacks, “And er, there’s a, one particular character in there called Leonard who I, …… it was for the first time, the first time I could identify with something” (2/230). This was a humanising moment for Christopher as he realised he was not the only person to have gone through what he went through (Hurwitz, Greenhalgh & Skultans, 2004). This identification can be explained in social cognitive theory (Bandura, 1991). This helped him to re-associate with the rest of the society.

It was many years before he was able to begin to make progress with his narrative, “Oh gosh, it probably started, be like the seventeenth year of it that I started to see a bit of light at the end of the tunnel” (3b/394): the metaphor of a tunnel indicating feeling disconnected and trapped in the dark (Berger & Luckmann, 1966). Before this progression occurred he did engage with what could be described as a dark occupation (Twinley, 2013) and that was hoarding, “And I hoarded. So, so (girlfriend’s name) had to contend with that and try and get me organised” (2/94). He suggests that the mess in his flat was representative of his state of mind at the time. His current progressive narrative may be influenced by the fact that now that he has a partner. They enjoy similar activities and she organises him. He sees that if someone organises him it makes for a more organised state of mind.

Christopher and his partner share challenges of living with a disability, hers being a congenital disability. He believes that although they have this aspect of life in common there is a difference between them, in that being born with a disability, “it’s bound to mold you in a different way” (2/20), suggesting psychosocial development being influenced by acquiring a disability (Erikson, 1959). She has a physical disability without cognitive impairment, which is another difference Christopher refers to, “I mean I don’t think she fully understands my limitations. Er, erm, which I can understand it must be difficult for someone who hasn’t got my brain” (3a/610). As someone with an ABI he still requires quiet time for himself, “having those quiet periods when you’ve got time to yourself is important” (3a/646), which is suggestive of hyperacusis (NHS, 2016).

His girlfriend was the catalyst to his narrative progression and he acknowledges this when he says,
"I used to describe myself as very aware I was like a car jacked up on bricks, spinning my wheels and not going anywhere… fortunately she, she gave me the time I required erm, to sort of erm, well sort me out" (3a/596-602).

This social capital made an impact of moving his narrative out of regression (Bourdieu, 1986). He has come to believe that people giving time to each other is far more important that money, “if another person gives you time, that’s the most valuable thing they can give you” (3a/630).

One of the main activities they share together is sailing. He had sailed as a boy, then windsurfed as a teenager. Having a partner who also has an interest in sailing gives him access to a sport that he would not have gone along to on his own as a disabled person. This is one of the few competitive sports where he has found a suitable infrastructure for disabled people to compete in, “Erm, cos a lot of things aren’t really open to us and er, the ones that are, are really like sideshows and things” (3b/64), reflecting the non-disabled hegemony in sport (Goodley, Hughes & Davis, 2012). He describes it as, “And er, it is a great erm, sporting environment for a disabled, for disabled people, erm, inspiring courage, inspiring, motivating and encouraging” (2/138). This is an opportunity for Christopher to challenge himself in a sport and move him outside of his zone of proximal engagement (Vygotsky, 1978; Csikszentmihalyi, 1990). They have aspirations to compete at an international level, but finances are limiting.

Development and agency are reflected in Christopher more recently by his undertaking a leadership course (McAdams, 1993), and he hopes this will improve his public speaking about disability issues. Previously the emotive element has prevented him from doing this successfully and he has broken down, suggesting that the ‘backstage self’ came to the fore, rather than remained hidden (Goffman, 1953). Whether or not to declare the invisible aspect of his cognitive deficits on meeting someone presents issues of social representations and making disability his primary identity (Moscovici, 2000), or can help in that it may encourage people to understand if he makes a mistake, “by telling people of my disability, that relieves, notches down some of the pressure I feel under” (3a/16).

Today Christopher (Christopher: photo1) runs a website where he shares his experience of disability, “er, this year got to point now where I’ve started to replace some
of that stuff that’s been lost” (2/112), indicating the intrinsic reward he gets from his activities (Csikszentmihalyi, 1993). He runs the website as part of a ‘quest’ to ensure that others do not fall into the same trapdoor as he did (Frank, 1995), which demonstrates his agency in moving his narrative forward and his desire to leave a legacy (Frankl, 1946). Part of his motivation to run this was due to an absence of ‘neuro-culture’ that he observed and that he had needed to ‘forge his own path’ (2/8). He touches on issues of the social construction of a disabled person and their low value to society (Berger & Luckmann, 1966), with this activity rebuking this idea, “It’s more about something that you personally value and erm, and you don’t’ feel like a third world refugee” (92/112). The website gives Christopher a significant degree of intrinsic reward, “But it gave me the outcome I was seeking” (3b/136), which suggests that it may have helped progress his narrative (Gergen & Gergen, 1986).

He challenges people who park in bays reserved for disabled people if they are not disabled, drawing on justice frameworks for disabled people (Hegtvedt, 2006), by reminding the public about protocol. He is aware of monitoring his own health and impact it can have on activities, “When my blood sugar’s low I’m more shaky” (3a/466).

He does Pilates based exercises for self-maintenance, “So I do my own exercises now, this morning, I do them every morning” (1/11), indicating that he is focused on having a
health locus of control (Rotter, 1954). He also reads about health issues to improve his understanding of this. Through learning about cognitive behavioural therapy he has linked exercise to mood, “if you’re feeling depressed or down or in a bit of a stupor then perhaps you need to go, jump on me trike and go for a ride” (2/333).

He is involved in two charities, one in the role as chair, “so I stepped up to the plate and now I’m Chair” (2/283). He mentions the social aspect of being involved and the camaraderie he feels, indicating the value of social capital (Bourdieu, 1986). The theme of learning through experience to move his narrative forward is evident when he talks about a time when the charity chose not to use him as the one to take their website forward, “Erm, so that was a bit of disappointment but erm, I’m just trying to think as to how I came across” (3b/132). This indicates that he is willing to reflect on critical incidents in his life (Dewey, 1938).

Christopher’s left-handed hemiparesis means that he has the ability to only use one hand and this is particularly frustrating for an individual from an engineering background, which involves practical problem solving. This has an impact on his living independently when he attempts DIY (Christopher: photo2).

Both his engineering and outdoor pursuit interests come together in work he is involved with for the national parks, where he advises on their local introduction of an off-road electric wheelchair, “it’s in a way it’s electro-mechanics, using my electro-
mechanical things to make things happen and it was achieving something that I couldn’t do for myself” (3a/1163-1167). This is an example of Christopher drawing on his occupational capital in his leisure / work activities (Cameron, Sadlo, Hart & Walker, 2016). He is then able to utilise the vehicle for rambling.

Adapting the regular form of cycling by use of a trike has allowed him to join a cycling club who are willing to accommodate him (Christopher: photo3). Being able to cycle with a group as opposed to alone offers him both protection from heavy traffic and camaraderie, “So I was in the middle of the pack as it were, which was quite nice as sometimes you can feel quite vulnerable on the road” (3b/264-266).

Christopher: photo3

He has reached some sort of resolution in his life today, “I can say now that I’m happy again with my life but it’s been a hell of a hard journey over 20 years” (1/7), drawing on the metaphor of life being a journey (Cashdan, 1999). He puts this down to re-establishing his self-identity, “It’s only when you re-establish some kind of self-identity that you’re in a way, you can make great, there’s a great improvement with your memory” (2/10). Resolution and harmony to one’s narrative can help turn psychic energy away from doubt, guilt, regret and fear (Csikszentmihalyi, 1990). It may be that his psychic energy being more at an equilibrium has made improvements to his memory (Sarason, 1984) and reflects the importance of being able to embody one’s identity and it’s affect on cognitive processes (Gelech & Desjardins, 2010).
Psychologically he has moved away from the social signifiers of status to recognising value in other aspects of life, “You feel like you’re, you’re a man of substance even though I’m poor as a church mouse… But I’m, I’m rich in many other ways” (2/30) (Berger & Luckmann, 1966). His counterfactual thinking leads him to consider what he would be like now if he had not acquired a brain injury,

“You know I could have perhaps considered myself you know being some kind of, sort of capitalist or something but er, but, but now that doesn’t interest me. And I erm, I’m more of a, I’m more intent on being a catalyst rather than a capitalist” (2/214).

The progressive element to his narrative more recently can be summed up in his statement,

“I mean it’s taken me a hell of a long time to say that I like my life again, but I do,erm.. it erm.. it’s a different life. It’s my life but it’s a continuation but it’s a new, a new journey. A new step and new life.” (1/7).

8.3.2 Analysis of narrative of a person who has a significant other with an ABI: Rita

Rita was a woman in her mid-forties who had married a much older man some three years previously. It was not apparent to her that he had an ABI until she was seeking an explanation for his behavioural issues some months into the marriage. It was then that he told her of his encephalitis as a young man. As with the previous account, no direct quote is offered from the reflexive diary as the diary content was subsumed into the positional aspects and subsequent analysis. Here is Rita’s story following ‘analysis of narrative’.

8.3.2.1 Positional aspects of Rita’s narrative interview

Rita appeared to take a very professional approach to the involvement in the research, being very smartly dressed and awaiting my arrival. I formed the impression that this engagement was part of a series of opportunities she had taken to be an advocate for people in a similar situation to herself and to her husband. I had not discussed my professional background as an occupational therapist and it seemed that this was not apparent to Rita during the interviews. She appeared to engage with me as a neutral researcher interested in stories of people living with
ABI. She was open in her discussions, revealing how she manages her social and personal identity.

Rita was an easy interviewee to warm to, displaying Christian values, such as compassion and being motivated by her faith. She was very articulate and reflective of her situation, being able to evaluate and interpret patterns of behaviour she saw in those around her. She appeared to be very intelligent. She used humour at times to illustrate some of the irony in her situation. It was obvious that our cultural backgrounds were different (from not only skin colour), when she talked about not growing up in a nuclear family and not necessarily expecting to have a traditional western-mother role with her own children.

8.3.2.2 Analysis of Rita’s narrative

Rita is in her forties and lives in a UK rural town with her second husband Peter, who is aged seventy. They have been married for approximately three years. When she married him she was not aware that he had had a brain injury in his early twenties, as it’s presentation had not been obvious in the social settings in which she conversed with him. The hidden nature of some symptoms is a common feature in ABI (Gordon et al, 1998). She is black, of African culture and she believes her current community to be both racially prejudiced and xenophobic to people from different countries, even different countries within the UK (Crowley, 1993). Having grown up in a collectivist culture she is often surprised at the individualist behaviour of some in the UK rural community where she now resides (Kantartzis & Molineux, 2014). She gave up work in social care in a UK city, to relocate and marry Peter and sees no immediate opportunity of being able to become employed: her carer duties require her to spend time with Peter as a priority. This impacts negatively on their financial situation. They live in local authority accommodation, which is unsuitable for their needs, but have been promised suitable, specially adapted accommodation in the future, after what she describes as, until recently “still fighting hard” (3/953). She finds that Peter has experienced a lack of acknowledgement of his need for support by the community and health and social care professionals in the past and she is trying to turn this around. Not only has his been a situation of poor social capital on which to draw, but there has also been a lack of support from health and social care statutory services (Bourdieu, 1986; Kneafsey & Gathrope, 2004).
Rita’s overall narrative tone is optimistic rather than pessimistic (McAdams, 1993). This may well be due to her Christian faith that guides her in how to live her life and the life choices she makes. This has been influenced by her formative years where she talks about the strong relationship she established with God. She attended a Catholic boarding school from a young age in Africa and became a Born Again Christian when she was thirteen. In an African culture it is not unusual to be brought up with members of the wider family rather than a traditional western family of two parents and siblings (Renzaho, Green, Mellor & Swinburn, 2011): she was brought up by an aunt and did not have a close relationship with her mother and so says “And er, I still feel that’s why maybe I loved God” (2/471), as a substitute for the relationship with her mother and this continues today. This strong religious legacy underpins her current narrative (McAdams, 1993). However, elements of her story display a pessimistic tone due to the difficulties she has yet to master and this tone is more evident when she talks about some of the issues she is still living with, such as describing the attitude of the local community, “You see this is how now what happens if you, you develop that hatred in yourself. It becomes you” (3/1219-1223). This is akin to a display of cognitive dissonance (Festinger, 1957) and may be due to the overarching romantic structure of her story driving the positive tone, yet she is currently the protagonist in a story where adversity is yet to be overcome (Frye, 1957). In other words, her carer narrative is ongoing (Frank, 1995).

In her young adulthood she progressed with her academic studies in Africa, gaining teaching qualifications and specifically with children with special educational needs. This is the first time in Rita’s story that she introduces the occupation of educating and special needs, which develops as her story progresses, “And then I developed interest er for children with special needs” (1/28). Much of her social life involved fellow church members and attending crusades as a Born Again Christian. She became revered for her singing in church. Involvement with church and spiritual engagement were significant occupations in her life at that time.

She came to the UK with her first husband and four children with the aim of studying in higher education, but also with a romantic notion that living in a different environment would improve her relationship with her husband. Here is an example of structuring her narrative as a romance (Frye, 1957). This second motive for emigrating was not realised and she divorced. She took up social care work in a UK city. Her ex-husband and his second wife have latterly, brought up her four children in Africa.
She still feels she has the role of mother although, “I, it’s not really hundred percent” (3/2449), but she ensures she contributes financially to her children’s education due to her responsibility and hopes that they will come to study in England in the future. Part of this disengagement with the mother role is due to the amount of time she has to devote to care for Peter and her cultural related values of ‘communal parenting’ rather than ‘nuclear parenting’. It is not unusual for carers’ roles to be negatively impacted on by absorption in carer duties in ABI (Lefebvre, Cloutier & Levert, 2008; Phelan et al, 2011). Rita’s more predominant roles of wife and carer engage her in an exaggerated amount of housework generated by her husband’s ABI symptoms. She also describes a role of being like a manager in a school in terms of living in the marriage and she draws on the skills of her past occupation in special education needs to cope with this, as well as her knowledge of social care services. This also suspends the romantic narrative structure of her story in the realisation that,

“It wasn’t a romantic, romantic marriage that I was in. I thought it would be (laughs). But now it was like I’m in a school er, and I’m, I’m also looking after somebody er, of things that I have to learn about and erm, practise, put them into practise otherwise it won’t work” (1/486-490).

This is a demonstration of a continuation of the occupational identity of the special education needs teacher, drawing on similar skills, akin to an occupational persistence or habituation, in coping with her day-to-day situation (Christiansen, 1999; Kielhofner, 2008).

There are episodes in her life that demonstrate a stable narrative e.g. after divorcing her first husband and him leaving the country, (even though she allowed him custody of the children so he would agree to leave). At other times she declares episodes of regression in the narrative e.g. marriage to her second husband, Peter, “And it’s now when my life changes.” (1/353) The structure of the narrative changes when she redefines goals in her life and gains autonomy, for example when she realised her husband’s symptoms were due to a long standing brain injury and she could separate the symptoms from the man (a progressive narrative structure) (Gergen & Gergen, 1986). She sees her husband as a valued person, who happens to have symptoms that can be understood and dealt with, similar to a child with special educational needs. This is a habituation, in the way in which she approaches her roles in life in the current day (Kielhofner, 2008). Overall, the narrative structure is progressive, though slowly progressive in parts e.g. the slow progress she is
making with statutory services and health services to acknowledge her husband’s symptoms and needs. In this way her story displays her as the protagonist in a story who has yet to overcome adversity (Frye, 1957).

Rita has a strong belief that God has a mission for her to look after Peter, and to turn his life around for him (overcoming adversity in a progressive and romantic narrative (Gergen & Gergen, 1986; Frye, 1957)). She entered the relationship with romantic notions of love and did not realise that he was looking for someone to care for him as he has struggled to cope with life for many years, due to the ABI symptoms. Her Christian values of compassion, respect and living a moral life maintain her in the relationship, even though her life has changed completely as a result of the role of wife and carer, with this high degree of adversity.

Objectification appears in Rita’s story in terms of how the local community has treated her husband in the past, and shunned him as a strange man, rather than trying to understand his behaviour in terms of the symptoms of his illness (Berger & Luckmann, 1966). She undoes some of the negative objectification in her own relationship by seeing him for the good man he is and “challenging these symptoms” (1/511). Furthermore, she finds herself objectified, through being of a different skin colour in a rural community that she sees as not only racially prejudiced but xenophobic to anyone from outside of the home nation.

Rita employs agency in her actions (McAdams, 1993), in that she actively promotes positive change and displays a number of examples of where she has changed her life as a result of having had difficulties in the past e.g. moving to the UK as an attempt to improve her marriage, allowing her husband custody of the children so as he would leave her life. At the present time she is ‘fighting’ for her second husband’s rights and her rights as a carer.

A number of months into her marriage, following behaviour from Peter that she could not understand, such as emotional outbursts (BSRM&RCP, 2003), he told of the time in his life when he was hospitalised due to encephalitis, which was a regressive turning point in his life (Gergen & Gergen, 1986). At this point Rita engaged with the brain injury charities, The Encephalitis Society and Headway. She describes the support she received from these non-statutory services as life-saving, “They have saved my life. They saved his life.” (3/2887). She continues with her occupation of education by educating people in statutory services who rarely come
across brain injury in their rural community, such as the GP and the social workers. She does this by way of obtaining leaflets on symptoms and their presentation in ABI, from the charities (Rita: photo1). Having the charities for support has given Rita power by gaining autonomy through knowledge and allowed her to have agency (McAdams, 1993).

Some of the symptoms of ABI Peter displays are fatigue, poor social judgement and inflexibility and obsessionality (BSRM&RCP, 2003; Headway, 2016b). For example, he can only bear noise in the flat at certain times of the day and Rita has learned to communicate by notes during those times, which has reduced his emotional outbursts. This is an example of how Rita has adapted the occupational form of the activity of communicating with her husband, to create harmony within the marriage (Nelson, 1988). She has also taken to wearing headphones so as he does not have to listen to the sound on the TV. Her pattern of activities has been compromised as a result of accommodating Peter’s needs (Martin, 2012). Each day they sit together and read, which Rita does not enjoy but she engages with the activity so as to connect with Peter, almost participating vicariously (Rita: photo2).
The adaptations are also similar to how a special educational needs teacher would adapt the occupational form of a classroom activity, demonstrating an occupational persistence or habituation in the approach to her role (Kielhofner, 2008), such as placing towels on the worktop to absorb the noise of placing dishes on it (this noise would trigger emotional outbursts due to hypersensitivity of ABI) (Rita: photo3).

Peter also bathes several times a day due to his obsessionality (Headway, 2016b). This leads to an excessive amount of time Rita spends on laundry (Rita: photo4) and is one example of how time spent on caring duties impacts negatively on her own occupational balance (Christiansen & Matuska, 2006).
Thus Rita draws on her occupational identity as a special educational needs teacher and social care worker to guide her current occupational engagement (Christiansen, 1999). She has adapted the occupational form of several of her husband’s daily tasks, to bring harmony to the marriage and become a manager to his life (Nelson, 1988). She sees it as her role to educate health and social care staff who do not understand her husband’s condition. Her knowledge of services and in taking a developmental approach has allowed her to solve some of his longstanding problems and she continues with this cause. She finds her life situation interesting and continues to uncover explanations as to why her husband behaves in the way that he does, linked to his brain injury.

She does get recognition of the positive changes she has made in her husband’s life, from people who have known Peter for a long time, “So yeah, I love so when they see me they, “Good girl, good girl.” “ah thank you I’m a good girl” (3/433). Her motivation to continue is because she sees housework as part of her role as wife and also, “my Christianity principle I’m doing it for God.” In caring for Peter she sees it as giving him life and is cognisant that he did not cause his brain injury as if he drank alcohol or took drugs. Rita is also conscious that it would not reflect well on her obtaining work in social care in the future if she left a man just because he had social care needs. This is an example of managing how she presents to others in everyday life (Goffman, 1959) and also protecting her occupational identity (Christiansen, 1999).

There are other examples where Rita is managing her social identity within the narrative. Women who live locally and have known her husband for many years
prior to her marrying him, suggested that she married him out of pity, almost
deriding her husband as a disabled man (Berger & Luckmann, 1966). She negated
these claims publically to them and suggested that the liaison is more one akin to
And yet at other times Rita uses imagery to describe the relationship that goes against
this very idea, such as being, “caught in a, in a net” (1/1706), as if she feels trapped in
the relationship (Mazaux & Richer, 1998). She also does not reveal to friends why
she cannot speak to them on the telephone after 8.30pm at night (a time when Peter
requires quiet). She considers it preferable to allow them to think that it is because
she is submissive in the marriage than due to his inflexibility and obsessionality. It is
as if social acceptability is more aligned with traditional family hierarchy and roles
than acceptability of a husband with symptoms of mental health issues (Berger &
Luckmann, 1966).

Her personal identity is very much as a Christian, “I have a Christian background”
(1/142). She finds ways to still engage with worship by listening to church services
on the internet through headphones when Peter demands quiet. In some ways,
adapting the occupational form of the activity of worship has allowed her to engage
with more fellow worshipers than if she attended the local church (Nelson, 1988).

The narrative is progressing by way of health and social care services now
engaging with Peter’s care. The occupational therapist has assessed them for living
accommodation adapted for their needs (COT, 2013) and they are currently waiting
for this. Rita continues to educate the GP and social workers about ABI and they are
expecting an appointment with specialist rehabilitation services, to which Peter has
eventually been referred. Rita is hoping to re-engage with some of her preferred
occupations by way of some respite care. Rita hopes to form an action group in the
community and raise awareness of the negative impact of not providing social
capital for all in the local community and being inward looking (Bourdieu, 1986).

Rita anchors her narrative to that of the parable of “The Good Samaritan”
(Widdershoven, 1993). Her extrinsic motivation is to live her life for God and she
believes that he has set her this task of not running away from a husband who has a
high degree of care needs and fails to give her the romantic marriage she hoped for.
The overall narrative is progressive and at the current time she is still experiencing
adversity in the midst of a narrative that may ultimately take the form of a romance
(Gergen & Gergen, 1986; Frye, 1957).
8.3.2.3 Additional notes

1. Rita identified herself and came forward to participate in the research as the wife and carer of a man with ABI. He has a history of encephalitis and in the absence of any support services she has engaged with head injury services. Peter displays symptoms of inflexibility and obsessionality that may be diagnosed as obsessive-compulsive disorder (OCD) in the future. As far as this research is concerned it is not known if this came before or after the ABI, but inflexibility and obsessional behaviour are common symptoms of ABI (Headway, 2016b) and it remains that Rita identifies herself as the wife and carer of a man with an ABI.

2. On contacting Rita eight months later for her to verify the plot of her story, her relationship with Peter had broken down, due to lack of support from outside agencies.

8.4 Chapter summary

This chapter continues Act III of the thesis, presented as a three-act story, in that it presents how the researcher attempted to further understand the issues of a disruption to narrative, occupation and identity due to ABI: it identifies the common plot typologies of the twelve participants’ stories and offers the analysis of narrative of two participants. In this study narrative tone and plot typologies did not always follow expected patterns, for example, with the majority of narratives being optimistic, despite biographical disruption. Having considered the narrative aspects of the data in this and preceding chapter, the Chapter 9 will consider the occupational aspects.
Chapter 9 The stories analysed: Occupational aspects

9.1 Introduction to the chapter

“He’d had a few drinks and it would just be again, kind of like a pattern. ‘I know what I can do and I can’t do it anymore’ and ‘You don’t know what it’s like.’ ‘I know what I could do.’ And I’m sitting there thinking, ‘Oh God I can’t bear this.’ And I’d just want to go to sleep and what could I say and I’m trying to do the counseling bit. And he will say, ‘You’ve always got your nurse’s hat on.’ That’s quite hard actually. ‘To, and what, how am I supposed to do this?’ How? What is right you know? Yes, it is my nurse’s hat. You’re right. And this is the wife’s hat. But the nurse’s hat is kind of like the way of coping with it.’”

This quote by one participant, Helen, illustrates how she drew on aspects of her occupational role as nurse to help her cope with her role as wife of a man who had acquired a brain injury. She utilised her nursing background as a way of moving forward with her biographical disruption.

This chapter considers these occupational aspects of the narratives, moving on from the narrative aspects in Chapters 7 and 8, and how these were integrated in the past and present of the life stories of the participants in this study. The persistent occupational patterns of the participants, whether they were still engaging with, or that they were influencing the narrative discourse, are presented. Barriers or enablers to engagement in occupation are considered as well as the coping strategies employed, with a caveat about the de-contextualisation of the presenting issues.

9.2 Thematic analysis of narrative data

This aspect of the analysis produced emergent themes from the data. Thematic analysis of narrative data is typically approached differently to traditional thematic analysis of qualitative data: themes can also come from whole, intact stories (Riessman, 2008), as well as themes from within the stories (Polkinghorne, 1995b). Riessman argues for analysis of narrative to produce themes from whole stories so as not to de-contextualise the data (Riessman, 2008). The underlying principle of this was adhered to in this study and produced a theme of persistence around long established occupations within the intact stories, which will be reported later in the chapter. However, it presented a dilemma for the researcher:
“My original aim for the research centred around uncovering those elements that enabled or presented a barrier to the participants engaging in their everyday occupations, living in a rural environment. It transpired that each participant’s story was so diverse in the nuances and contextual circumstances that no overall theme, from the whole stories, transpired from these particular aspects to report in the research. However, the occupational persistence in the stories did and is arguably far more interesting a phenomenon. So do I set aside the barriers and enablers to engaging in occupations and the rural issues from the analysis, when this is what I had led participants to report on to me, or am I ethically obliged to still present them?”

Furthermore, the narrative psychological approach adopted in this study revealed themes of interest from the coping strategies employed by participants, to facilitate occupational engagement.

A decision was made to acknowledge the themes coming from within the narratives, despite being de-contextualised from the whole narrative, with respect to the following: Barriers and enablers to engagement in occupations due to ABI; Strategies employed to cope with engagement in occupations due to ABI. These are summarised in Appendices T and U (Tables 13 and 14).

For this reason the results and analysis of the de-contextualised themes are presented, arising from a thematic analysis of the data arising from the narrative psychological analysis method (Crossley, 2002). This is presented in Sections 9.2; 9.3; 9.4. This type of thematic analysis is justified in that it has been utilised in a wide variety of narrative studies (Polkinghorne, 1995b). However, the emphasis for this study is placed on the main thematic analysis presented later in this chapter, relating to occupational issues coming from the whole narratives, where context is contained (Riessman, 2008). Further justification for the importance of holding on to context comes from an excerpt from the researcher’s reflexive diary at the end of the second interview with Participant 11, Diana. Her son had a brain injury sixteen years earlier and Diana had told a story with many positive aspects. Below is an extract from the researcher’s reflexive diary:

“We waited for her daughter to arrive. Diana wanted to introduce me. I’d assumed her daughter would be like her, calm and loving. When she came in she was angry and loud. She didn’t give me eye contact and swept past me, waving her hand. She told me there was no use ‘doing a survey’ on her mother, if I didn’t find out how it affected the rest of the family too. She told of how her and her brother had been very close (crossed her fingers and raised them and said ‘like that and now what?’). She told a tale of dealing with his aggressive outbursts when he’d come close to hitting her. She shouted about his hoarding and coping with that. Diana looked mildly embarrassed and tried to explain how she’d mentioned these things then said, ‘It’s funny how I put the bad things out of my mind and try to only think of the good
So although barriers and enablers to engaging in occupation are presented, as well as coping strategies, in no way do they represent a conclusive picture, even with respect to any one individual with an ABI.

**9.3 Barriers and enablers to engagement in occupations due to ABI**

Five main themes emerged that were considered a barrier or enabler to engagement in occupations that may have affected both participants with ABI and/or impacted on the significant other (SO): 1. Symptoms of the ABI and other health factors; 2. Social capital, infrastructure and support; 3. Stigma; 4. The emotional impact; 5. Rural living issues.

These themes will now be presented, with the caveat that each individual with ABI, or SO in the life of someone with an ABI, engages in occupations within an individual context. These issues by no means impacted on all, due to the nuance of circumstance (hence the reluctance to de-contextualise the data as discussed earlier).

**9.3.1 Symptoms of ABI and other health factors**

As might be expected, the many and varied symptoms of ABI, impacted on the lives of many of those who participated in the study and their subsequent occupational engagement. These could be categorised into three sub-themes: 1.1 Physical limitations: 1.2 Behavioural and cognitive issues: 1.3 Emotional issues.

**9.3.1.1 Physical limitations**

Physical symptoms were limiting factors for all participants with an ABI to some degree and was also reported on by SOs. In addition to this some SOs had their own health issues that impacted on engagement in occupations. The most frequently occurring limiting physical symptom of ABI was fatigue. One participant, Sam (ABI: P2), explained why he had decided to give up work due to fatigue:
"And I was just fed up of coming home and thinking I’m absolutely and utterly exhausted. So now I’ve come home, the bit of time I should be enjoying, I can’t because I’m so tired.”

Sam (2/1137-1139)

Some participants experienced mobility issues, due to the specifics of their ABI, such as a hemiplegia affecting both mobility and function. Shopping was affected for one participant who lived alone (Hilary, ABI: P6), as well as her being able to climb steps to access services such as a dentist. Other symptoms discussed were nighttime epilepsy, tinnitus and visual impairment. A change to the sense of taste stopped one participant from socialising with friends at a similar developmental stage to her, as she could no longer drink alcohol due to the unpleasant residual taste.

Auditory and visual hypersensitivities were also reported. One significant other (Rita, SO: P12) described how her husband could not bear to hear the sound of pots being placed on the kitchen work surfaces. The auditory commentary of the television was unbearable for two of the husband’s of SO participants. Thus watching television as a shared occupation became less interactive, due to the partner with an ABI wearing headphones. An example is offered about the way in which hypersensitivity affected Bruce’s (ABI: P4) social interaction and leaving the house:

“If there were two or three people in here and they were, they were all talking I would switch off I would get very confused and wouldn’t make effort to talk back. That er almost like an overload. Happens with my eyes as well. If I go in a car I often have my eyes shut or I look down.”

Bruce (1/90-100).

Sexual dysfunction was mentioned by one (Helen, SO: P7) with an impact on the marital relationship. Two participants with ABI mentioned hair loss, not only impacting on gender identity, but for one (Hilary, ABI P6) this had the resulting impact of not being able to go swimming as it would involve removing her wig in public. Naturally, people whose lives are affected by ABI are not immune to other health issues: both a participant with an ABI and one SO had a neurological condition that was degenerative. Although neither participant reported how this affected their engagement in occupations at the time of interview, they were aware it would impact in the future.
Altogether, the physical issues presented a mixed picture, due to the complex array of potential symptoms following brain injury, but fatigue was a prevailing concern that impacted on engagement in occupations.

### 9.3.1.2 Behavioural and cognitive issues

Behavioural issues were reported in the stories of several participants, especially by SOs, though acknowledged to a lesser extent by some participants with ABI. Two spouses of men with ABI mentioned anger and volatilty from their husbands (Rachel, SO: P1; Rita, SO: P12). Another acknowledged her husband’s past anger (Elizabeth, SO: P10), but explained it away as frustration with his ABI predicament, as was also self-reported by one participant with ABI (Sam, ABI: P2).

An excessive and obsessional bathing routine resulted in one SO (Rita, SO: P12) having to undertake extensive laundry duties, carried out in the public arena of a social housing complex laundry room. This impacted on her social identity in that she was pitied for being married to a man with unusual habits. Obsessive behaviour in terms of hoarding caused anxiety for one SO: a mother (Diana, SO: P11) was aware of the impact on her son’s reputation with neighbours i.e. his social identity, as a result of the hoarding. The social identity issues from disinhibited behaviour, both for her son and herself, became amplified in social situations when her son had alcohol. Below is an exert from her transcript describing his behaviour at a family party:

“I mean at a party you were there for a long time. You could see they were starting to get ‘Oh God. This fella’s getting on my nerves!’ He was getting on mine as well. And (daughter) and I were trying to you know, get him to be quiet. ‘(Son) behave yourself!’ But that was doing the wrong thing. But of course, there again, he was having wine, er, that wouldn’t help, the fact that he was getting alcohol into him. But er, we’ve never been back down to (daughter’s) since.”

Diana (3c/182-198).

A vast array of cognitive issues were reported as impacting on occupational engagement for people with ABI, by both participants with ABI and SOs. For some, executive functioning issues or sequencing, clouded performance with even taken-for-granted daily living skills such as dressing and performing kitchen tasks. Memory issues, both long and short term were common for people with ABI in the stories of participants and had an impact on multiple aspects of daily occupations, such as maintaining employment and studying. Poor attention span, lack of orientation to date and time and visual perceptual issues were mentioned in individual situations of those with ABI.
9.3.2 Social capital, infrastructure and support

Issues arising from social capital, service infrastructure and support dominated the narratives in terms of barriers to engagement in occupations. Support from statutory services was supplemented by non-statutory and informal support, but many issues were left unresolved from the perspectives of both participants with ABI and significant others.

9.3.2.1 Social capital

A primary domain of support for participants with ABI and SOs came from within family and social circles. Participants were grateful for support they received from family members and spouses, though some family relationships were strained or had broken down due to the behaviour of the person with ABI, in some cases leading to total rejection. Conversely, one participant (Helen, SO: P7) saw coping with her husband’s ABI as leading to recognition from her father that she was a capable person, which was a source of personal satisfaction.

“Erm, well I think he, he, he has a very close friend, xxx and she said, “Your Dad’s very proud of you.” And I kind of know that but it’s not something he’s gonna say. So that was she, “You know he doesn’t know how you cope.” And I, so I suppose that there’s more kind of mutual respect if you like. He, he was a bit of a distant father.”

Helen (3/1685-1687)

Engaging with friends was also a support mechanism for both the person with an ABI and SOs. Conversely some had seen relationships dwindle, for a range of reasons, such as no longer having shared interests or no longer being able to function well in social situations due to memory loss. One participant with ABI (Angie, ABI: P3) found it difficult to find friends other than with people who had disabilities.

All of this study’s participants had some connection with related charitable organisations, as one would expect from the recruitment method. That said, for all, the social capital offered by the charity was hugely beneficial and enabling. This was mainly from the aspect of receiving information, advice, social outlets and companionship, though some were active contributors to the charity as part of their repertoire of occupations. One SO (Helen: P7) saw her husband’s ABI as having led to meeting interesting people she otherwise wouldn’t have and engaged in activities through the charity that pushed her boundaries. However, support was not always
accessible at the time of the ABI. Below is an exert from the transcript of one participant, Christopher (ABI: P8), who found no support outside of the family once discharged from statutory services:

“I was aware that I was living an inverse of the life I previously led. Erm, so it was obvious to me that it wasn’t, it wasn’t gonna be the same. Erm, and erm, so I couldn’t, and plus I was in a situation where I had no comparable anything. And erm, nothing I could relate to or compare with. That’s you see, you’ve got all these things contributing to an immense feeling of loneliness. And erm, but erm, on that, yeah, that’s why it was so intensely black. Erm, and erm, but, but er, but one of the things as I said that I forced me on this quest was the fact that there was, there was no sort of I used to refer to as neuro-culture. Things that I can relate to and associate myself with because of, I was in a place that nobody had really been before. Erm, and no, and yeah, I was forging my own path.”

Christopher (2/4-8).

This led to him developing a website to support others who may have a similar experience. Barriers in the community were reported in terms of the environment not being wheelchair-friendly and a lack of investment in disability sports.

9.3.2.2 The benefit system and finances

Some participants were reliant on state benefits for finances, due to having to give up work with ABI. Being disbelieved by benefits agency workers or the agency not understanding the complex and variable nature of ABI, presented barriers to engagement, as well as stress and anxiety:

“he doesn’t feel the job’s beneath him cos all he was doing was collecting up rubbish. But it’s the fact, it’s the carry on he has when he loses all his housing benefit. And then he’s gotta reapply for it again. Nothing’s simple.”

Diana (3b/41-43).

Cuts to Housing Benefit were causing anxiety around the spare room subsidy, though being able to access a Motability car was very much appreciated.

9.3.2.3 Specialist services for ABI

All participants except one discussed some aspect of statutory services that had left them with dissatisfaction, to variable degrees. In the most serious cases this was inadequate emergency care that contributed to the ABI itself. One participant with ABI (Sam: P2) felt he was viewed as a malingerer before his diagnosis, as a judgment on his working class status by his GP. Several participants were unhappy with the model of care delivery post-ABI: they weren’t listened to by health professionals, which was dehumanising.
Two SOs (Helen: P7; Doug: P9) were upset that small positive changes in their partner’s progress were not acknowledged when reported to their consultant:

“Dave was trying to, he was talking him and then he remembered, I think it was his consultant’s name. And he said, “Oh that’s great for me. Remembering her name.” And I thought, “that is a major achievement.” And the Cons, the psychiatrist just sort of took no notice. I thought, “Oh God.””

Helen (1/24).

One participant with ABI (Hilary: P6) was mimicked and ridiculed by nursing staff for having speech difficulties. Secondary health conditions were reported as having better health services: for cancer and Parkinson’s. Longer-term statutory services were identified as still being needed though absent, by people several years post-ABI as progress was still being made. A dialogue of wanting ‘rehabilitation not care’ came through several narratives.

Three participants lived in social housing and one was satisfied with the service they had received and two weren’t. One participant with ABI (Hilary: P6) had been placed in a care home for elderly people with dementia when she was in her 40s, was asked to leave when her finances ran out: she was incapable of finding alternative housing without help. A lack of specialist knowledge from social workers and a lack of continuity and choice in care were also issues.

### 9.3.3 Stigma and identity issues

Some participants lived with an ABI and no obvious outward physical signs of it. This led to one participant (Hilary: P6) being labeled as an alcoholic by the local community due to her unsteady gait. One SO’s (Diana: P11) son with ABI was verbally abused and told was a ‘benefits cheat’ by a neighbour, because he helped with her gardening. Benefits Agency staff were also disbelieving of some participants’ diagnoses (Rachel: P1; Sam: P2; Hilary: P6).

The invisible disability in the workplace led to a dilemma as whether or not to divulge the diagnosis for one participant (Angie: P3). She could either explain needing more time to complete tasks but risked prejudice from the disclosure. Examples of social and personal identity issues were frequently cited, such as being stigmatised and shunned by the local community, being pitied, with the brain in particular having its own stigma-related issues, over and above a physical disability.
One participant’s ex-partner preferred to let relatives believe she was drunk than reveal her ABI:

“At one of his family’s weddings and I couldn’t walk in a straight line down the aisle. And he told everybody I was drunk.”

Hilary (2/622-626).

Some people reported losing friendship groups. Two participants with ABI (Angie: P3; Hilary: P6) regularly utilised coping techniques in private, such as cue cards, but did not feel able to use them in public, due to it singling them out as ‘different’. One participant (Doug: P9) did not want to holiday with other disabled people, as he and his wife did not identify with this social group. However, two SO participants (Helen: P7; Elizabeth: P10) felt that their children were more accepting of disability, through identifying with a father with ABI.

9.3.4 The emotional impact

All but one participant reported some form of a negative emotional impact from life with ABI, which impacted on their day-to-day life. The only SO who did not mention this had married her husband after his ABI and took it as part of who he was. Reaction to the trauma itself was reported by several participants: one participant with ABI described nightmares; one SO (Helen: P7) had a period of hyperactivity and trying to control her world; one participant with ABI (Christopher: P8) continued in a similar vein for over ten years. It’s impact led to one participant, Hilary, experiencing alopecia. Here is an extract from Hilary’s transcript:

“The doctor, the doctor said it came out of stress… It, it, you feel naked. A bald man is attractive, a bald woman is a freak…but it’s stress, caused by stress.”

Hilary (2/1010-1024)

Stress and anxiety, from day-to-day coping, striving for the pre-injury self or the fear of an unknown future, was reported by many participants. The stress also exacerbated memory issues, where they existed due to the ABI, which had a negative impact on functioning. It caused marital strain in some of the participants’ relationships, though was not reported in others. One SO (Helen: P7) felt under stress due to her husband’s suicide risk when she was at work. Another (Doug: P9) managed a team of paid carers for his wife’s day-to-day living and the role conflict of being manager and husband led to him not being able to relax in his own home. Depression was mentioned by several participants, with ABI and SOs, and past
suicidal ideation from two participants with ABI. Low self-esteem was discussed by two people with ABI.

Guilt was apparent in the stories of three participants: guilt for past behaviour towards parents in the early days of the ABI (Angie: P3); guilt for not protecting his wife from negligent medical staff that led to the ABI (Doug: P9); guilt at having had a son, who now had two ill parents and for preferring to spend time outside of the home than with her husband with an ABI (Rachel: P1). Conversely one participant (Helen, SO: P7) said she preferred her husband with his ABI as he was less of a perfectionist now and she had become more outgoing and confident at having to engage with occupations he previously did, such as driving, cooking and organising the home.

9.3.5 Rural living

The peace and quiet of the rural environment held a benefit over and above natural beauty for a number of participants with ABI. Quietness was preferred where hypersensitivity to noise was apparent. For one participant with prosopagnosia (Angie: P3) there were less people to offend when not recognising them:

“I don’t know, guess it’s the fear of you know, bumping into an old school-friend and not having a clue who they were.”

Angie (3/695).

People knew her in the village and were supportive of this issue. Being known in the local community helped for some (Hilary, ABO: P6), in that shopkeepers gave extra time to handle money when participants were buying goods. However, one SO (Diana, SO: P11) thought that her son had become stigmatised by local residents and another was strong in her declaration of the inward-looking community where she and her husband with ABI lived.

Infrastructure and statutory support varied widely between rural environments of participants, with one participant moving to a rural area from an urban area 200 miles away for better head injury services. Conversely, others found such services lacking. Public transport also varied, which made the driver role significant for several participants. But overall, ten of the twelve participants had preferential reasons for living in a rural area.
9.3.6 The impact on roles

Both participants with ABI and SOs experienced a range of issues that impacted on their roles on a day-to-day basis. Roles impacted included husband, wife, driver, worker and friend. However, each circumstance was different with no clearly identified trend. For example, although a number of SOs discussed how their marriages had been tested, a participant with an ABI discussed how it had brought her marriage closer (Susan: P5):

“Erm, I think since I’ve had the hemorrhage it’s brought us a lot closer. I think it either does one way or the other.”

Susan (2/10)

For another participant with ABI (Hilary: P6) the relationship broke down altogether. Where SOs were in marital relationships the discourse was clearly not centred on care in terms of having a wife or husband to be ‘looked after’, but instead a marital relationship that had challenges to overcome, requiring rehabilitation and moving forward. As mentioned above, one SO (Helen: P7) thought that in some ways the marriage was better, as her husband was less of a perfectionist and she had tried more roles, such as driver and cook, after her husband’s ABI. This had helped her to become more outgoing than when her husband had taken charge pre-ABI.

Six participants had to give up their worker role due the ABI. All but one were participants with ABI. This had an impact on finances and occupational identity. However, one participant with an ABI (Christopher: P8) had become an advocate for people with disabilities and described himself in the quote below:

“You know I could have perhaps considered myself you know, being some kind of, sort or capitalist or something but er, but, but now that doesn’t interest me. And I erm, I’m more of a, I’m more intent on being a catalyst rather than a capitalist. And erm, and that’s the way I kind of live me life now.”

Christopher (2/124).

The driver role was an important factor for a number of participants, in that having an ABI often meant relinquishing this, sometimes to their wife, which caused gender identity issues for two participants. Still having the driver role was considered important for one participant with an ABI (Christopher: P8) as he lived alone in a small rural village. One SO (Rita: P12) had a period of time where she was worried about her husband still driving due to safety issues, but he had since given this up.
Role conflict occurred in the situation of being a manager of his wife’s care (Doug: P9), whilst also being the marital partner: paid carers whom he managed were always in the house, even when he was in his night-clothes. Another SO (Rita: P12) felt that she had to protect her occupational identity as a care worker: she felt she couldn’t leave the marriage as it would be viewed as uncaring. However, working together was something that one SO encouraged (Elizabeth: P10), developing a business with flexibility to suit her husband’s limitations and sharing the business tasks:

“We’ve started a business together. Which is in early days, but we’re hoping it builds up so I can take that next step and move work and do that properly. We’re happy.”

Elizabeth (1&2/5)

9.4 Strategies employed to cope with engagement in occupations due to ABI

From within the narratives, a variety of different coping techniques could be identified, but again, each was individual to the particular circumstance of the participants. The strategies were collated into the following categories: managing identity; drawing on social capital; positively moving forward in life; adopting practical coping techniques; adopting particular behaviours; and engagement with spirituality.

9.4.1 Managing identity

Identities were managed in various ways within the telling of the stories. For example, some significant others took care to present their loved ones in a positive light and highlight their strengths. Some identities were rejected, such as significant others rejecting a carer identity and stressing partner identity instead. Disability identities were also rejected by some, as well as one SO (Rita: P12) managing social identity by rejecting the calls from neighbours that she had married her husband out of pity.

One participant with ABI (Sam: P2) justified his position as being unemployed, by declaring the contribution he had made to the workforce over many years. Others carried their previous professional identity forward, even though they had not worked in that field for some time. Here is an exert from Susan (ABI: P5), talking about nursing:
“Erm, I think really since I was 16 I’ve been a nurse.”

Susan (1/10).

Comparison processes were employed by some, such as comparing their own situation with others and identifying with case studies e.g. from published literature. Social signifiers of status were clearly rejected by one participant with ABI (Christopher: P8), by considering himself as a more wholesome person:

“You feel like you’re, you’re a man of substance even though I’m as poor as a church mouse. But I’m, I’m rich, er that’s one of the things I used to say well I am as poor as a church mouse but I’m, I’m rich in many other ways.”

Christopher (2/112).

Some guarded their identity of having an invisible ABI in social situations, such as work, in case it invited prejudice. One SO (Rita: P12) took time to separate her husband’s symptoms from the person he was, as well as personally identifying with the parable of *The Good Samaritan*, in that it encouraged her to stay and care and do ‘God’s work’.

9.4.2 Drawing on social capital

All participants used social capital to help them cope to varying degrees. This has been discussed in 9.3.2.

9.4.3 Positively moving forward in life

Several of the participants acted with agency to move forward in life, some actively challenging themselves or setting goals to achieve, some using schemata to frame their situation was drawn on by some participants and some by challenging medical staff who played down small progress:

“And I’m one of them people cos I’ve gone through stuff with my own family, hospitals, doctors, surgeons and nurses, I know. I recognise things and I sort of had a quiet word with him after and said, “Where’s your bedside manner gone?” The way he just spoke to my husband was appalling. I said it was like, “Do this. Do that. Boo bom. See you Monday, bang. Goodbye.” And he actually said he was sorry, came back in and explained.”

Rachel (1/36)
Some saw life as a project, a journey or conceptualising adversity as a romance to be survived and have an improved life as a result (done by two SOs who were hoping for improved marital relationships than pre-ABI).

A number of participants displayed resilience, for example by perseverance, looking past the problems and being pragmatic, or simply acknowledging their situations and normalising day-to-day life as far as possible.

9.4.4 Practical coping techniques

For those with cognitive issues their coping strategies involved some practical techniques, such as using cue cards and diaries for executive functioning issues and memory. Headphones helped for some with auditory hypersensitivity. One participant with ABI (Hilary: P6) was aware that her social skills had left her less inhibited in social situations and she found that she had to actively avoid telling the truth of what she observed about people, so as not to offend them.

“When I learned to speaking, I know this probably sounds stupid, but I wasn’t editing my speech. So what I thought, came out my mouth and it’s mortifying.”

Hilary (2/487-489).

Paid help, statutory and non-statutory services were used by some: physiotherapy, vocational rehabilitation and counseling were all used. One participant (Elizabeth, SO: P10) began a door-to-door sales business, with flexible working, so as her husband could be meaningfully employed after other jobs had failed.

9.4.5 Adopting particular behaviours

Two SOs (Rachel: P1; Helen: P7) discussed their own obsessional behaviour, for example excessive cleaning following the actual ABI. Two SOs (Diana: P11; Rita: P12) discussed the obsessional behaviour of their loved ones:

“He still collects an awful lot – rubbish. I mean I wish he’d stop it but what can you do?”

Diana (3a/435-441).

Avoidance or distraction behaviours were also discussed, such as going out to avoid being in the house with a husband with ABI (Rachel: P1), or changing work so as not to come across people with similar diagnoses (Susan: P5).
Conversely some positive behaviours were also discussed. Several participants were pursuing a path of intrinsic reward by helping others. One participant with an ABI was creating a legacy for others with ABI (Christopher: P8), by developing information services. One SO (Doug: P9) created opportunities for people with disabilities to enjoy adventure weekends. Another (Hilary: P6) discussed the importance of taking part in research so as others could be helped.

9.4.6 Engagement with spirituality

Issues of reification and placing life in the hands of fate or a higher being, were discussed by several participants:

“I could quite happily go and say sit in a church for an hour and just be quiet. Erm and just think well if he’s listening to me you know, what the hell am I supposed to do now?”

Rachel (2/791-797).

One brought up the issue of superstition. One participant with ABI (Christopher: P8) saw their circumstance as an opportunity to have a greater appreciation of life itself. Two participants (Rachel, SO: P1; Helen, SO: P7) discussed living in the present time instead of worrying about the future, almost adopting an approach of mindfulness.

9.5 Occupational analysis of whole narratives

Attention now turns to a thematic analysis of narrative, as preferred in narrative research, so as not to decontextualise the data. This involves interrogation of the narratives to identify themes from whole narratives. So how were the narratives structured in terms of engagement in occupations and what theme, if any, emerged from the analysis of whole narratives in this study? The participants in this study told their stories, as anyone else would, under the influence of their own individual and their culture’s stock of stories. Participants will have revealed their inner narrative to some degree (Polkinghorne, 1998; Hanninen, 2004). This element of the analysis aims to offer explanation beyond the text, in terms of engagement in occupations and living a life impacted on by an ABI. The results come from an iterative process of studying the data in its multiple forms, beginning with the initial transcripts and video data, through to populating the coding frames for analysis, to the production of the whole narratives: occupational influences were identified (Appendix V, Table
15). Multiple perspectives on the data are possible, but as this research adopted an occupational perspective on lives following ABI the data was viewed through an ‘occupational lens’.

9.5.1 The emerging pattern of a persistent theme in occupations

The initial consideration turned to the occupational employment role, past or present, of the participants. These are presented in Table 3. The occupational aspects of the participants’ daily lives, along with the occupational discourse within the narratives were then considered, to see if connections, patterns or persistent elements existed.

Table 3: Work occupations of participants

<table>
<thead>
<tr>
<th>Participant number / pseudonym</th>
<th>Significant other (SO) or person with an ABI</th>
<th>Work occupation</th>
<th>Past or present</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Rachel</td>
<td>SO</td>
<td>Housewife</td>
<td>Present, but past desire was to become a nurse</td>
</tr>
<tr>
<td>2 Sam</td>
<td>ABI</td>
<td>Factory / shop worker</td>
<td>Past, but past desire was to be a history teacher</td>
</tr>
<tr>
<td>3 Angie</td>
<td>ABI</td>
<td>Social care manager</td>
<td>Present, but past desire was to become an occupational therapist</td>
</tr>
<tr>
<td>4 Bruce</td>
<td>ABI</td>
<td>Policeman</td>
<td>Past</td>
</tr>
<tr>
<td>5 Susan</td>
<td>ABI</td>
<td>Nurse</td>
<td>Past</td>
</tr>
<tr>
<td>6 Hilary</td>
<td>SO</td>
<td>Pharmacist</td>
<td>Past</td>
</tr>
<tr>
<td>7 Helen</td>
<td>SO</td>
<td>Nurse</td>
<td>Present</td>
</tr>
<tr>
<td>8 Christopher</td>
<td>ABI</td>
<td>Engineering PhD student</td>
<td>Past</td>
</tr>
<tr>
<td>9 Doug</td>
<td>SO</td>
<td>Human resources / finance manager</td>
<td>Past</td>
</tr>
<tr>
<td>10 Elizabeth</td>
<td>SO</td>
<td>Teaching assistant / nursery nurse and self-employed shopping business</td>
<td>Present. Has had a number of entrepreneurial ventures</td>
</tr>
<tr>
<td>11 Diana</td>
<td>SO</td>
<td>Mother</td>
<td>Present</td>
</tr>
<tr>
<td>12 Rita</td>
<td>SO</td>
<td>Special educational needs teacher / social care worker</td>
<td>Past / present</td>
</tr>
</tbody>
</table>

Case examples have been selected to illustrate that patterns and persistent elements of work occupations were found in the narratives of both those participants with ABI and significant others (two examples of each). Further to this, whilst Rita’s and Christopher’s examples come from individuals who had had higher education in
their work occupations, Rachel’s contrasts this in that she had never formally worked in that occupational role, but aspired to it and informally worked in it. Hilary’s is an example of someone with significant cognitive impairment: persistent elements of occupational discourse were difficult to extract initially, but careful reading of the text revealed that an occupational persistence remained to a degree.

9.5.1.1 Case Selection 1: Rita: the special educational needs teacher and social care worker

Below is an exert from the transcript of participant, Rita, who drew on her occupational past of being a special education needs teacher to progress both hers and her husband’s narrative, having just uncovered his past diagnosis that explained his behavioural issues:

“At first I couldn’t understand why he would shout for nothing. And I didn’t realise that he was shouting because he was struggling with something he’s thinking about and he’s trying to, to, he’s failing to communicate and also he, I realised that he couldn’t talk to me in the mornings. And in the evenings he just wanted total silence and at that time he would just tell me, “Honey please if you want say, tell me anything, can you write for me.” So and in the mornings and in the evenings if I have to talk to him, tell him anything, I have to write.

Now I have, I, it is not my life had, have had to let me just say, has changed. I’m no longer the manager I was. Now it’s a different manager like in a school. Because I have to learn and to talk to my husband only not… using notes. But it’s because I was reading now the information why… and understood his problem. And er, I felt good now that I’m doing it. To communicate with my husband, it’s not bad, now we have to communicate in order for him to do something in a nice way. I have to write, not to talk. So I had to learn to communicate with my husband using notes.”

Rita (1/564-584).

In the quote it can be seen how Rita drew on her approach to behavioural issues with special educational needs children in her past occupational work role, to deal with her husband’s behavioural issues arising from the style of communication within their relationship. She utilises the discourse of being a manager in a school. Furthermore, she illustrates how she conceptualised her marriage situation of dealing with behavioural issues, with how she would do so if she were a manager in a school and put an alternative method of communication into practice. When her current engagement in occupations is considered it reflects other aspects of having to perform those occupations in a manner that is congruent with her husband’s hypersensitivity or ritualistic behaviour.

9.5.1.2 Case Selection 2: Rachel: aspired to be a nurse
Below are a series of exerts from the transcripts of participant Rachel. Rachel was the wife of a man with ABI and did not ever take up a professional career. Her occupational work history was as a factory worker and a housewife. However, she held aspirations to become a nurse from being a teenager:

“I mean in my day then there was like the job, not careers off…. Like careers’ officers then and you could leave school and I wanted to do either A & E, maternity ward or surgery… or psychology… of some sort. I so wanted to do it.”
Rachel (2/516-522).

“I got accepted in Nottingham and… for a place, and his words were, “You walk out the house, you’ll never see your Mother again. You make your bed and lay in it young lady.” And that was when I was like sixteen, seventeen erm so I never signed the thing and rang up and said, “Sorry, Mam’s too poorly.” Erm So…”
Rachel (2/562-578).

Her story progressed with details of nursing her mother at home until she died, becoming involved with charities, as an advocate for people with neurological conditions and also helping as a Pat Dog volunteer. Towards the end of the same interview she tries to sum up her perspective.

“What have I done? Cos all I’ve done is been kind, helpful nice..., tolerant of situation and tried to help in every way I can. I’ve never turned me back on or, you know, abandoned everyone.”
Rachel (2/690-700).

Rachel did not achieve her aspiration of becoming a professional nurse, due to her father giving her an ultimatum of either nursing her mother at home or being cut off from the family. However, a persistence in occupations continues through her life story, of helping and adopting nursing attributes. At one point she offers her opinion on how a professional nurse should behave and what she did when this fell below her expectations.

“(Nurse) spoke up and said, “Yes, there is, there is that. We do have a psychiatrist. We do have counselors, erm at the oncology unit. And yes you can, you know at (hospital name). And you can talk to em and if (husband) wants anything I’ll send you a load of paperwork through.” Erm, but that never happened. Still waiting for the paperwork! Quite surprised to say that she was a (charity) nurse. In fact I walked away from that hospital that day with more from (previous hospital) and more in my head from the matron and my own personal looking at the computer the actual tumour that was (husband’s).”
Rachel (1/86-88).

The narration continued with her own interpretation of the symptomatic aspects of her husband’s tumour and his resulting psychological behaviour resulting from it. The narrative displays persistence in adopting a nursing perspective.
A persistent theme of adopting related occupations can be seen clearly in eleven of the twelve participants. A summary of this is presented in Appendix V: Occupational aspects of the narratives.

9.5.1.3 Case Selection 3: Hilary, pharmacist

This pattern of persistence in occupations was less pervasive in the narrative of participant Hilary. Her ABI occurred ten years prior to the data collection and her occupational work background was as a pharmacist, with experience in classified advertising. Much of her daily living activities at the time of the data collection centred around her own rehabilitation, in a developmental stage of devising and implementing problem-solving techniques. This was done with the assistance of paid carers to teach her to manage day-to-day life. However, elements of drawing on her occupational past were evident in the fine detail of the interview transcripts.

Below are two exerts from one of her interviews:

“So yes I could categorise. It’s now I have problems. I’ve got, I can read cos I know the sounds the letters make but I can’t do the alphabet or anything like that. Anything of order, in order. Erm, even though I know, I even know the Russian alphabet but I can’t do the English alphabet. Jump backwards and forwards in it and I can’t add up. But I’m improving … But I used to have to do formulae in my head and now I can’t, even with a calculator, add up my shopping now, you know. But there’s ways round it. Erm, I think of numbers that make what I call a whole and like 20 and 80’s a pound and that kind of thing. 2 pounds and 8 pounds is 10 pounds. It’s anything in between I’m totally lost. You know it’s, it’s just one of those things.”

Hilary (3/111-138).

The interview continued with her being asked for further clarification.

Researcher: “But are you, are you finding any other coping strategies for helping with this as well?”

Hilary: “Yeah, I use, that to tell me what day it is (points to magazine) and people. That was my idea. Erm, and the numbers things is just a pharmacy technique. Cos there are a lot of numbers that are repeated in pharmacy. Erm, so you get, you got to know the figure, after a while. And so I reckoned if I could memorise a figure, you know that way. You know. So it’s a similar technique to 2 tablets 4 times a day makes how many in a week.”

Hilary (3/139-158).

Although Hilary’s overall pattern of occupations did not form a strongly consistent theme, there was an obvious strategy of drawing on her past occupational schemata to implement day to day coping techniques. She drew on cognitive techniques,
learnt from her occupational past in pharmacy, to manage the numerical task within the handling of money, in order to buy daily provisions in the local shop.

9.5.1.4 Case Selection 4: Christopher: the PhD student in engineering

Below is an excerpt from the transcript of participant, Christopher, who drew on his occupational past of being an engineering graduate and PhD student to progress his narrative, having become frustrated when traditional therapeutic interventions were having little impact on his rehabilitation following his ABI:

“But when it came to a stroke, I was just lost. I didn’t have the necessary erm, abilities to er regain my previous physicality. So erm, I, I got very frustrated with having to do these exercises cos they, they, they, I never received any benefit, feeling, any feedback from them. Er, it was a bit of a closed, sorry is that right, open loop situation. Erm, and those, as I know from my education opened up systems are very bad. Er they’re the ones that fall out the sky. Erm, so I, I, I realised that the way I was going, I was just on a hiding to nowhere really and I had brain damage and it, I was told it would you know, the brain, there’s a, brain damage is brain damage. It won’t come back, it, or repair. All you can do is work round it and set up new systems or whatever. Erm, so that’s what I attempted to do and that was the, the way I viewed my, everything I did in the future.”

Christopher (3b/360-384).

In the quote it can be seen how Christopher drew on the cognitive schema of his engineering background to find ways of coping with his situation of living with an ABI. He utilises an engineering discourse to describe his predicament. Furthermore, he discusses how he conceptualised his own life situation in terms of a broken engineering system and how he realised that he had to change to a different kind of system if he wanted to progress (when traditional rehabilitation methods were not working for him). When his current engagement in occupations is considered his engineering background is further reflected in his choice of daily activities such as home repairs, sailing and cycling, even with a longstanding hemiplegia.

Work occupations, past and present, within the data of the other participants were explored to consider occupational links between the work occupations of participants and other occupational aspects of the narratives.

9.6 Chapter summary

This chapter has presented the results and analysis with respect to the occupational aspects of the narratives. This forms part of the paradigmatic analysis or analysis of narrative. Traditionally the de-contextualised themes would not be the preferred
data presentation within a narrative study, but a justification is offered for this, in terms of the barriers, enablers and coping strategies for engaging in occupations. In addition, thematic analysis of the whole narratives generated one overall theme: an occupational persistence was displayed in that occupations from the past influenced the engagement in occupations in the present, be it engineer, nurse or a long held desire to be a nurse. The chapter serves as a contribution to Act III of the thesis presented as a three-act story, in that it goes some way to resolving the story in terms of a disruption to the narrative, occupation and identity due to ABI.
Chapter 10  Discussion

10.1 Introduction to the chapter

"I mean, I’d love to go over on the train, but anyway we will go. But as I say, I’ve never been to Scotland. I’d love to go, I’d love to go down to Cornwall. I’d also like to go over to Belgium. I’d love to do erm, Battlefield Tour, see where me Dad went running up the beach, in Normandy erm, and er, take it from there."

This quote by one participant with ABI, Sam, comes towards the end of his interview when he expresses his future narrative. It exemplifies Arthur Frank’s point (1995), that most people with an illness spend the majority of their time not being a patient i.e. not the focus of a biomedical model, as in this case Sam’s hopes for being able to visit new places on holiday, one of which holds special meaning to his past. It places Sam’s story as a personalised and highly individual one, linking back to the stories his father told him of the war as a child. As with all people whose lives are impacted by ABI (the same as those not impacted by ABI), their narrative is linked to past experiences.

This chapter considers what the telling of the narrative reveals about how people construct new occupational relationships with their post-ABI worlds. The potential utility of the twelve narrated stories in this research study is proposed. Discussion turns to the narrative tone of the twelve stories and whether these display a pessimistic or optimistic tone in light of a disruption to biography. Consideration is also given to the goodness of fit with narrative genres and typologies. Barriers and opportunities to engagement in occupations that arose out of life being affected by ABI, with particular note of the rural setting, are explored. The socio-cultural milieu is considered with respect to identity and social capital. The overall theme of occupational persistence that arose from the twelve emplotted stories is analysed, and offers an explanation of how this expands with respect to the development of the individual. The chapter closes by contextualising the study outcomes within current occupational therapy practice, before presenting the limitations of the research and potential future research.

10.2 The utility of the narratives

So what can be learnt from the narratives of the twelve participants in this study: six people with ABI and six significant others in the lives of people with ABI? Do the narratives have a utility for health professionals or others in similar situations where
life is impacted by ABI? And does a rural location influence this post-ABI experience?

10.2.1 Utility of the twelve highly individualised narratives in storied form

One might expect the stories of the participants with ABI to differ in nature to those of participants who were significant others, as this former group of participants had experienced actual physical trauma as well as having biography disrupted. But perhaps the psychological trauma of ABI impacts so much as to affect anyone closely affected to the person with ABI. In actual fact each story was individual and quite different from the next, across both groups of participants. The variation in the narratives is likely to be linked with the highly individualised nature of human experience and narratives functioning within the mental realm of individuals to influence an awareness of self (Polkinghorne, 1998). Taking the methods of the study into consideration too, the researcher offered a broad remit for participants to relay a breadth of personal experience during the data gathering stage, with the initial asking of a broad single question: this could have further helped produce the detail in differing accounts (Wengraf, 2001). Furthermore, the question at the outset of the data collection made it clear that the interest of the study lay in an experienced-centred narrative, in order to draw out occupations, as opposed to an event-centred narrative i.e. not the actual event of the ABI (Andrews, Squire & Tamboukou, 2013). Thus twelve highly individual narrative accounts resulted, revealing individual identities and repertoires of occupations.

So what examples of this breadth of difference are there in this study? One such example of variation is presented here: for participants with ABI little similarity was evident in functional status with respect to being in employment: Angie (ABI: P3) was working but did not disclose her disability at work; Sam (ABI: P2) was giving up work due to fatigue; Susan (ABI: P5) returned to work following the ABI then retired from nursing due to the physical demands; the other three ABI participants had not been in employment since the injury. Yet some narrated experiences sat outside of traditional ideas about work and non-work. Christopher (ABI: P8), who had been a PhD student in engineering, was able to legitimise not being in paid employment and still declare his worthiness, whereas this was a continuing source of de-legitimisation for Hilary (ABI: P6) who had been a pharmacist (Berger & Luckmann,
This might not be surprising when one considers the amount of exposure individuals have to information in day to day life in the 21st Century, including multiple constructions of possible ways of living and identity constructions (Rustin, 2000). One can summise and suggest that Christopher had achieved representative status, by way of his adopted roles of chairing a charity and building a website for establishing a 'neuro-culture', thus allowing him to feel less stigmatised by unemployment (Goffman, 1963). Hilary's cognitive and physical limitations meant that much of her personal resources were spent on coping with day-to-day life, (although at one point she had significantly contributed to setting up a new charity branch). However, it does make it difficult to predict what content may appear in the narrative of someone with an ABI, or a significant other of someone with an ABI. Each is specific and individual.

So how might these twelve highly individualised accounts of life affected by ABI be utilised? Was anything accomplished for the individuals narrating their life experience, how might the whole stories be useful to a potential future audience and if so, of whom might this consist?

10.2.1.1 The participant’s use of their own narrative

Attention first turns to a potential understanding of what might have occurred for the participants in telling their story. Being a serious illness, which then transpires into a day-to-day life experience (for those with ABI and significant others), the established life map of the past, with its imagined destination, will have become lost or obscured. The future narrative is less certain than it was previously, as well as how life might be lived. In the process of sharing the story with an engaged listener (in this case the researcher) an opportunity will have arisen to absorb the listener's reaction. This could facilitate the constructing of new understandings of their own circumstance for current understanding and future options (Frank, 1995; Lorenz, 2010). Previous identities may have been lost or given up as a result of circumstance and a change in occupational engagement and roles will have occurred in most participants' lives. For example Rachel (SO: P1) made reference to her husband’s negative behaviour due to his ABI impacting on family relationships and her role as sister. Angie (ABI: P3) talked about how her own negative behaviour from twenty years ago, at the time of her injury, impacted on her relationship with her mother. Mattingly (1998) proposes that in the telling of the story it allows an individual to situate their current circumstances, by way of a social-
sense making, which moves the narrative forward. The telling of the story can help to reduce discord when a life has been interrupted and its examination makes it more worthy (Ricoeur, 1991). Verbalising the experiences may have facilitated a reflexive monitoring of the present and future in light of the past (Frank, 1995).

But is there any evidence that any such processes were taking place as result of individuals telling their stories to the interviewer in this study? Indeed there is no way of actually knowing if any such processes were or were not taking place and it would be bold to suggest that it were in order to reinforce theory: participants were not asked to comment on this aspect of the study. The initial engagement to take part in the study was not specific enough to suggest that individual life stories would be reconstructed about each participant, for the specific research method, but what participants did know was that they had produced a photographic record of day-to-day occupations, held on a camera loaned to them.

Rachel (SO: P1) had been telling her life story since being a child, due to her earlier experience of caring for a mother with a degenerative neurological condition. The proposed sense-making process in telling the story and finding coherence might suggest that Rachel should by now have reached resolution in the understanding of her own story. Yet in many ways it followed a ‘chaos’ typology (Frank, 1995). That is not to suggest that sense-making has not been taking place over the course of her life, but her life story has been called on to respond to further challenges during its course.

However, three participants voluntarily asked if they could have copies of the photographs sent to them after their involvement with the interviews, which was duly done, potentially indicating a higher degree of ownership or interest to the told life stories and social validation of it.

10.2.1.2 Use of the narratives in health and social care settings

Consider now the public stereotyped image of an individual with a brain injury, or being a significant other in the life of someone with a brain injury. Discourse typically carries negative connotations, suggesting those impacted as inferior and less in control of their own lives. When families come into contact with brain injury services, where the day-to-day focus is working with people in challenging circumstances, the professional discourse lies within multiple encounters of tragedy, uncertainty and
seeking repair for symptoms that the individual is now experiencing (Weatherhead & Todd, 2014). Despite Frank (1995) reminding us that patients spend only a small amount of time being patients and the majority of time experiencing life, is there an awareness of this imbalance in the medical / patient interaction? Within the healthcare encounter the focus is on the current circumstance, as deduced in the healthcare assessment, with past experiences and identity frequently de-legitimised in the encounter too (Mattingly, 1998). Although the discourse between medical practitioner and patient is two-way it is asymmetrical in nature, due to the medical expertise of the doctor and designated duty of care to those in the ‘sick role’ (Parsons, 1975). The health professional’s viewpoint may thus be out of alignment with that of the patient (Gelech & Desjardins, 2010). Furthermore, in times of biotechnological advances, the medic not trained in listening to and understanding service-user stories, will typically defer to the laboratory diagnostics instead and prefer not to defer to narrative forms of information (Hydén & Brockmeier, 2008; Easton & Atkin, 2014).

So were any such issues coming through the participants’ narratives in this study? Indeed almost all of the narratives expressed some form of dissatisfaction with not being listened to, a medic not acknowledging small steps in progress or a disalignment with health or social care services, the most extreme case being Rita’s. Rita was unable to get her husband’s GP to acknowledge that her husband had a brain injury until she sought leaflets from charity-sources that explained symptoms that the GP could readily observe.

When this type of encounter with statutory services does occur, not only is there a disappointment and frustration at not being able to access services required to help with day-to-day life, but a disempowerment is experienced too. All communications require a speaker and a listener (Polkinghorne, 1998). By not being listened to the speaker, Rita (SO: P12), had no power, when she sought services for her husband with ABI. However, she persisted, sustaining her moral status behind the suffering, with an accompanying taken for granted moral claim for assistance and was eventually listened to (Charmaz, 1999).

But not everybody has to pursue services for assistance with ABI quite so vigorously; and presumably services are adequate and beneficial when available. Where services have been accessed for rehabilitation the emphasis points more towards physical, cognitive and behavioural remediation than emotional and
psychosocial dimensions of an individual’s circumstances (COT, 2013; Weatherhead & Todd, 2014). This would fit with assessment encapsulating more measurable and standardised testing in the healthcare settings, especially in a UK NHS aligned with evidence-based practice and allotting monies to proven interventions (Laver Fawcett, 2007). However, the more complex, harder to measure facets of self, such as identity and social interactions in a naturalised setting typically remained unprovided for. Even in situations where the individual had had a brain injury for many years, two significant others in this study (Diana, SO: P11; Rita, SO: P12), identified social interaction as an issue for their loved one with ABI and neither had been in receipt of services for many years. For example, if Diana’s son had been assessed in healthcare services with respect to the domains of physical, cognitive and behavioural aspects, his needs might be significantly met, yet assessment of emotional and psychosocial aspects (not commonly measured) might have revealed a need for intervention (indeed they were ignored when they requested treatment for his low mood, even though there are high rates of depression post-brain injury) (Cantor et al., 2005; Cocks, Bulsara, O’Callaghan, Netto & Boaden, 2014).

So could the twelve narratives from this study have potential in contributing as exemplars of a life impacted by ABI, be it an individual with the ABI themself or a significant other in the life of someone with an ABI? And are there examples of what narratives can add to the typically used healthcare discourses? New understandings about life impacted by chronic illness can emerge from narratives and identify the limiting nature of typical healthcare interactions (Ironside et al., 2003). These narratives could potentially highlight the inadequacy of healthcare goals focused on improving functional outcomes, especially when such outcomes have been defined by practitioners, rather than the individual service users. Furthermore, narratives offer an opportunity to highlight the limiting nature of commonly objectified language of healthcare, in that the lived experience element is missed (Ironside et al., 2003) e.g. terms such as ‘mobilises with assistance’ gives no indication of the experience of trying to engage in a balanced range of occupations, like visiting a shopping centre, accessing public transport or mobilising in a work situation.

In her narrative, Rita (SO: P12) repeatedly failed to be able to engage health care services for her husband with ABI and respite for herself. She found herself not listened to during encounters with professionals, in that her husband appeared to be functioning relatively well as a man of his age, yet her experience of living with a
man with symptoms of OCD and the resulting emotional and psychosocial issues for both herself and her husband were not acknowledged. Susan (ABI: P5) felt objectified as a patient following her ABI event, when described by her diagnosis, at a time when she was already feeling very vulnerable. Sam (ABI: P2) felt that he was dismissed as a malingerer by his GP, in not being listened to about his declared symptoms leading up to his ABI. Both Helen (SO: P7) and Doug (SO: P9) felt deflated when a hospital consultant failed to acknowledge small improvements in their partners’ abilities.

Acknowledgement has already been made to the narratives being constructed as opposed to being true, in that the truth or realist position is not claimed in this study. However, they do reflect the experience of living a life impacted by ABI and the heterogeneity of those experiences, which is potential valuable learning material for those engaged in healthcare work.

10.2.1.3 Use of the narratives for others in similar situations

Chapter 3 discussed the capacity of narratives for the people who read them, as well as those that tell them, in that within a story possibilities can be envisioned and choices for future action formulated. People can become caught up in stories and although they may be telling of someone’s past, they may be working to form ideas about the reader’s future (Frank, 2010). This is underpinned by the idea that human experience is inextricably linked to the realm of meaning in life and thus exposure to new experiences will impact and adapt meaning for people. Hearing the experiences of others facilitates a deliberation of thought and meaning, creating alternative possible scenarios about how to act (Polkinghorne, 1988).

This offers the potential utility of the narratives with those in similar situations to those who have told them. The experience of biographical disruption can force an individual to consider new relationships with the world in which they live, due the loss of the previous life track they were pursuing (Frank, 1995). The individual may well look for voices of others who share what they are going through and need the narrated thoughts of these people in similar situations so as to be able to become aware of their own thoughts (Frank, 2013). Narratives by nature offer insights into difference and the extra-ordinary, and are examples of less frequently found cultural scripts. Thus these can provide explanations of how circumstances occurred and guide future ways of how to act (Mattingly, 1998). Indeed whilst many sudden illness
stories describe a biographical disruption, some offer less tragic accounts described as ‘biographical flow’ and may help in offering hope for more positive outcomes (Faircloth, Boylstein, Rittman, Young & Gubrium, 2004).

But most people who experience an ABI, with their families, will have some contact with an expert medical practitioner who should be able to explain possible future scenarios and likely functional outcomes, so why might this not be sufficient to explain possible new relationships with the post-ABI world? This links back to what was discussed earlier about healthcare interactions being primarily focused on functional outcomes, in the domains of physical, cognitive and behavioural issues, with little acknowledgement of the emotional and psychosocial aspects that impact so heavily on personal experience (BSRM&RCP, 2003; COT 2013). Furthermore, in modern day healthcare, with a paternalistic approach, once symptoms have been discussed, the medical practitioner becomes the spokesperson for the disease, and their discourse is one of a specialist language, which is set apart from that of the person with ABI and their family commonly (Frank, 1995). This distancing in the communication style is further emphasised for the person with an ABI if they have cognitive difficulties. Hearing the narratives of others, in familiar language and where the conversation has moved on from functional issues to those of experience, offers an opportunity to locate the self within them to imagine future possible scenarios.

Drawing on the twelve participants’ interviews in this study some examples of being able to locate the self within the stories of others can be found. Helen (SO: P7) drew on the story of a television drama, where the wife of a man with ABI was sent home without help, similar to her own circumstance. It made her realise that she had an advantage over the wife in the television drama in that she had the additional skills in being a nurse. Christopher (ABI: P8) identified with a man in a book by Oliver Sacks, who was similar to him in that both were completing a PhD at the time of the injury. It was the first time Christopher had found anyone to identify with, even several years after his brain injury occurred. Christopher talked about this being a milestone and a humanising experience for him. The twelve stories generated in this research have the potential to serve a similar purpose for others whose life is impacted by brain injury.
10.3 Barriers and enablers to occupational engagement and coping strategies employed

The analysis of narratives identified a number of issues from within the narratives about how participants' engagement in occupations was restricted or enhanced with life impacted by brain injury. So what might some of these issues be and what influences might there be in trying to overcome the impact on daily life?

10.3.1 Living with the symptoms of ABI and the consequences

The participants in this study experienced the ABI several or many years earlier (between four and 48 years). So were they still living with a variety of symptoms that were impacting on daily life, be it the individual with the ABI or those who were significant others? And how might these symptoms impact on being engaged in occupation, such as being employed?

10.3.1.1 Physical symptoms

Indeed symptoms were very evident, wide-ranging and varied, the most common symptom being fatigue (BSRM&RCP, 2003). This was a contributory factor to leaving employment, needing to sleep during the day or go to bed very early, interfering with family life. For example, it caused one participant to fall over and ruin his partner's Christmas tree, causing irritation. Mobility issues were apparent for some due to paralysis or ataxia and impacted on them or their partners, (BSRM&RCP, 2003). This limited the ability to visit places with environmental barriers, be it a public venue or the home of family and friends, especially in the situation of needing a wheelchair outside of the home. Being able to get on and off a bus with ataxia, coupled with language deficits was difficult for one participant. Nighttime epilepsy meant that one significant other had become used to a poor sleep pattern over three decades, though had become used to managing this. A partner’s sexual dysfunction and its relationship impact was mentioned by another significant other.

Very specific and uncommon symptoms were discussed by some, which led to a much more generalised impact on daily life. Hyperacusis, or intolerance to everyday sounds (NHS choices, 2016) was a barrier to daily living for one participant and one
significant other whose partner experienced it. Parageusia, or unpleasant changes to the sense of taste (Headway, 2016), meant that one participant with ABI (Angie, ABI: P3), avoided alcohol and certain foods, leaving her distanced from her young adult peer group with whom she previously socialised (further compounded by fatigue and cognitive perceptual disorientation to time and place). Direct coping techniques were employed by the participants in such circumstances, such as using headphones to block out noise of day to day family routine and diaries for orientation and aiding memory (Bruce, ABI: P4; Rita, SO: P12). Statutory therapy services and charities had been involved in helping some participants with specific techniques, but some had devised their own, through experience and problem-solving. For example, prosopagnosia left one participant (Angie, ABI: P3) unable to recognise work colleagues and remember details about them to engage in casual conversation, so she kept up to date with daily news to have topics for discussion. Another had learnt how to regulate her conversation, having offended people with disinhibited speech in the past (Hilary, ABI: P6). Altogether, this serves as a reminder to the highly individualised scenario for problem-solving and overcoming ABI symptoms in everyday occupational engagement for people whose lives are impacted by ABI and a role to be played by both individualised service provision and trial and error experimentation by individuals.

### 10.3.1.2 Cognitive and other psychological issues

Cognitive issues for those with ABI affected work engagement in some situations. For example one significant other (Helen, SO: P7) told of her partner’s alexia (not being able to read) (Coslett, 2000) forcing him to leave his job as a nursery nurse. The complexity and specificity of cognitive issues such as memory, attention, insight and social judgment peppered the participant narratives. Behavioural issues of those with ABI, had occurred at various points in the life stories for several participants, potentially triggered by adjustment to the newfound situation (BSRM&RCP, 2003). One participant (Sam ABI: P2) made reference to this with no elaboration, whilst for his partner (also a participant, Rachel, SO: P1) it had been a significant factor in her life, due his emotional outbursts and protracted low mood over several years. One significant other (Diana, SO: P11) and her family were well aware of the low mood of their family member with ABI but were repeatedly unable to access mental health services with his healthcare being restricted to brain injury services with it residing in a physical health domain of the NHS. The emotional impact had led to treatment for depression for one significant other (Doug, SO: P9).
10.3.1.3 Symptoms impacting on engagement in occupations

So what are the implications of symptoms of ABI becoming part of daily life and how does living with the reminders of a serious long-term illness impact on engagement in occupations, including employment? In Chapter 4 it was discussed how the sudden impact of ABI differs from aging, with respect to continuing to engage in the daily repertoire of occupations, in that aging sees a change and adaptation over time (Griffith, Caron, Desrosiers & Thibeault, 2007), whereas ABI brings about sudden change. However, it might be expected that over time, the participants from this study would have been able to make the transition to regain occupational balance (Lund, Mangset, Wyller & Sveen, 2015). However, all of the participants with ABI were of working age, yet only one was in employment (Angie, ABI: P3) and then she had to engage considerable coping mechanisms to be able to maintain this. Even if people feel alienated from their work roles, work does bring status and allows opportunities to afford leisure pursuits (Dant, 2003). Not only does being unemployed bring financial pressures for daily living, but also the intrinsic rewards of being engaged in work and the opportunity for a positive experience is denied (Morris, 1888; Wilcock, 2000a; Wilcock & Hocking, 2015). This constitutes a potential severance to the link between occupations and occupational identity (Alsaker & Josephsson, 2013; Blank, Harries & Reynolds, 2015; Nayar & Stanley, 2015). Having experienced a forced withdrawal from work occupations, the resulting challenge to identity and life roles would potentially impact on self-worth and self-esteem (Preston, Ballinger & Gallagher, 2014) and mental health (Cotton, 2012).

There was also an impact on significant others and work engagement: four of the significant others were of working age, one of whom could not seek work due to caring for her husband (Rita, SO: P12) and another had her own health problems (Rachel, SO: P1). Another worried about her husband whilst she was at work (Helen, SO: P7), with anxieties ranging from if he would remember to collect the children, to would he take his own life. This constraining of daily occupations and forced change to the daily repertoire of occupations for significant others is not uncommon (Hasselkus & Murray, 2007; Martin, 2012; Heward, Molineux & Gough, 2013), potentially bringing similar issues for significant others, as for those who have experienced the ABI.
The non-facilitatory socio-cultural environment can lie behind the difficulty that many people with long standing health conditions find in re-establishing suitable employment (Townsend et al., 2009). Indeed understanding and support from employers and work colleagues has been found to be key to successful return to work for those with ABI (Rubenson, Svensson, Linndahl & Bjorklund, 2007), which includes coping and emotional support (Donker-Cools, Daams, Wind & Frings-Dresen, 2016). However one significant other (Elizabeth, SO: P11), who had run her own business a number of times in the past, began a new business from home that her husband could be part of and worked around his impairments. This was in contrast to vocational opportunities he had tried and been unsuccessful with in the past. So it would seem that there is the opportunity to adapt individual socio-cultural environments to successfully engage someone with ABI in employment, in this situation it was by having a partner with clear locus of control to facilitate this (Rotter, 1975).

But even if vocational rehabilitation and supportive workplaces were readily available for individuals with ABI how might the complexity of the symptoms such as cognitive impairment impact on the type of employment opportunities? The individual would be most likely to be offered work in the unskilled labour market, especially disappointing if they have been skilled or a past member of a profession and continue to hold strands of that identity (Nochi, 1998; Carroll & Coetzer, 2011; Gelech & Desjardins, 2011). At a collective level the socio-cultural environment determines what types of occupations are valued, or considered worthy, with the western cultural focus of becoming a particular worker or professional and developing the personal identity. Thus being unable to work or subsequently being offered the opportunity to engage in work of a lower status may impact on the individual, leaving them feeling marginalised or confused around occupational identity (Christiansen, 2000; Townsend et al., 2009; Phelan & Kinsella, 2009; Laliberte-Rudman, 2010). Intrinsic needs of expression and fulfillment may become quashed (Hammell, 2004). The concept of doing, being, belonging and becoming through occupation and the three-way association of survival, health and occupation may become severely compromised (Wilcock & Hocking, 2015). An occupational imbalance due to too few occupations is typical (Eklund, Erlandsson & Leufstadius, 2010).

So if the individual with ABI was compromised in occupational balance by being under-occupied with respect to work, was this scenario similar for significant others
in this study? Certainly a number of the participants experienced the reverse, especially where they were the significant other of a person with high support needs. Even where the significant other was not working, due to age or circumstance, life was extremely busy with much time spent on activities related to their loved one’s symptoms and the subsequent social co-ordination of occupations for both parties (Christiansen & Matuska, 2006; Harvey & Singleton, 2009). Of course occupational gaps following ABI are not just restricted to work as an occupation (Eriksson, Tham & Borg, 2006) and the impact on occupations for socialising will be discussed below in ‘10.4.3 Managing identity’.

10.3.2 The ABI experience enabling occupations

Having discussed barriers to engagement in occupation presented by ABI and wanting this study not to be drawn into the usual negative focus of ABI research (Hayas, de Arroyabe & Calvete, 2014), were any opportunities presented with respect to engagement in occupations as a result of the ABI? This was indeed discussed by some participants. For one significant other (Rachel, SO: P1) it brought her husband’s attention to connect with more spiritual aspects of life, which had been absent in the marriage before and they subsequently enjoyed visits to a Buddhist retreat together. Having given up work due to fatigue, one participant with ABI (Sam: P2) now had time to spend on his crafts at home and he had a strong desire to create something as a legacy for his son, as he had had nothing physical to remember his own father by. These two examples suggest an existential meaning behind engaging in the occupations they cited, gaining connection to others through participation (Frankl, 1946/2004). This re-evaluation of life’s priorities and values and spirituality following ABI has been found elsewhere (Conneeley, 2012).

Highlighting this even more are two other examples: one participant with ABI (Christopher: P8) had been on course for a promising career in engineering before his ABI. He suggested that if he had not had his injury he may have become a ‘capitalist’ and instead viewed himself as a ‘catalyst’, helping others who find themselves in the same situation as he did many years ago. One significant other (Rita, SO: P12) believed that she existed in her caregiver’s role as God wanted her to be ‘A Good Samaritan’ and had set her this challenge. Frankl’s idea of ‘creating a work or doing a deed’ (2004, p115), Maslow’s hierarchy of needs (1943) and the theory of doing, being, belonging and becoming (Wilcock & Hocking, 2015) might underpin the participants’ motivations for occupational engagement here.
An additional issue to be borne in mind is that acquiring a brain injury, or becoming a significant other in the life of someone with ABI, can happen to anyone and those affected will be subject to the normal vagaries of daily life, such as other medical diagnoses. In particular in this study one significant other (Rachel, SO: P1) had a degenerative neurological condition herself, as did one participant with ABI (Susan: P5). These are additional individual complexities of life affected by ABI and serve to remind that neat categorisation of the impact of a medical diagnosis is simplistic.

10.3.3 Managing identity

So what issues emerged around the participants’ identity, what explanations lie behind this and why might people whose lives are impacted by ABI feel the need to manage their identity, be it publically or personally? The data revealed examples of being pitied, verbally abused and wrongly assigned negative labels in the community. Additionally some participants held on to their past professional identities, such as nurse, engineer or pharmacist. There was a reluctance to use coping strategies in public that drew attention to cognitive deficits, such as cue cards for dressing when going swimming at the public baths. An impact on occupational identity has been discussed above. Attention turns to social identity theories to explain the issues that emerged.

10.3.3.1 Social identity

In the narratives the individuals perceived themselves as belonging to social groups e.g. engineer, nurse, pharmacist and thus will have perceived themselves as having the attributes and characteristics of those groups. This serves to define the individual’s social identity (Tajfel and Turner, 1979). The social groups that one aligns to offer labels that bring a sense of who one is. So the participants defined themselves for example, as being a mother or being an engineer etc. and with these labels would come additional elements of self-esteem and fortune associated with those groups (Brown, 1996). Social groups often attract stereotypes as labels and in turn the individual would have begun a process of self-stereotyping by being a member of the group, associated with the group’s characteristics (Tajfel and Turner, 1979). So when one participant, Diana (SO: P11), experienced her neighbour labeling her son as a ‘benefits cheat’ it prompted great distress.
Social identity relies on a double motion: people perceiving similarity to those of the same background (in-group similarity), whilst perceiving difference to those of other groups (intergroup or categorical differentiation) (Deschamps and Devos, 1998). This perceived difference has been previously reported, when adults with ABI described their social isolation due to being categorised with labels such as head injury and disability overriding all of other statuses (Conneeley, 2002). By association there is a possibility that this may spread to their SOs.

In this study almost all participants, whilst not overtly declaring a social identity of head injury or carer of someone with ABI, strongly identified with brain injury charities and saw such organisations as supportive and a place to find a connection with like-minded individuals. One significant other (Diana, SO: P11) connected so much and admired the people she met at one charity meeting that she ironically suggested that everyone should experience head injury in order to acquire their positive characteristics and shared understandings. This would suggest an enlargement to the personal values held about which intrinsic qualities can be special or valuable (Cantor et al., 2005; Conneeley, 2012).

Interestingly the use of the term ‘carer’ was initially adopted in this study then replaced by the term ‘significant other’. It became evident during recruitment and interview that some significant others did not identify with the social group of ‘carers’ as they still held primary roles or identities as husband, wife, mother etc. and did not foreground their loved one’s identity as someone who needed care: they rejected head injury and disability as the overriding statuses, in contrast to typical healthcare encounters, where professionals’ primary contact is with people who are ill or have impairments (Conneeley, 2002; Weatherhead & Todd, 2014).

A complex array of psychic disturbances is experienced by an individual who acquires a brain injury, with varying degrees of disruption to physical and cognitive abilities (Mazaux and Richer, 1998). This can have a significant impact on the social ability of the person, in terms of being able to maintain past relationships and establish new ones in different spheres of daily life. This could prevent such individuals from joining social groups, or indeed attempts to maintain membership of those pre-injury social groups post-injury and was discussed by Angie (ABI: P3). However, a continuation of sameness of self pre- and post-injury has been reported in the literature and explained as important to the individual’s preservation of
personhood (Medved & Brockmeier, 2008). Thus Angie would be affected by not being able to join or maintain the pre-injury social groups.

Connections and obligations to others are shared through occupations and add to the individual's sense of being and belonging (Wilcock & Hocking, 2015). These were potentially disrupted with life impacted by ABI, yet still held on to by those in this study and reported elsewhere. For example, even though one individual with ABI (Susan, ABI: P5) had not been employed as a nurse for some time she talked about being a nurse in the present tense, holding onto her nursing social identity. Similarly others were keen to foreground their past occupational identities from many years previously.

Participants discussed how social groups had been lost, explained by no longer having things in common with them or not understanding why they were no longer included. Formation of the concept of social identity is a result of cognitive processes from a self-evaluation of opinions and abilities: a social comparison process (Festinger, 1954). Opinions and abilities to make judgments about the self are influenced by social interactions and self-opinions and judgments may be altered if external feedback indicates a need for this. It is not uncommon with ABI to hold incongruent ideas about the old and new abilities (Conneeley, 2004). Festinger (1954) further proposed that if there is a range of people offering different opinions about abilities, people select those people closest to themselves in opinions and abilities to make our comparison with. Also people change their opinions and abilities to be closer to others in a group, as well as trying to change others in the group to be similar to themselves, resulting in a move towards a cognitive uniformity. Thus in social groups others may move away from those affected by ABI if they assess them as being different. This may explain some of the situations participants described.

The implications for an individual with an ABI could be a distancing from them by others without a disability. Alternatively the person with an ABI may need to find a way to manage identity by reducing difference to others in the social group. This also provides a strong reason for protecting a negative identity by participants in this study. For example Angie (ABI: P3), kept her prosopagnosia hidden at work and instead implemented strategies to hide it. Similarly Rita (SO: P12) publicly declared love for her husband to fend off suggestions of marrying for pity, as suggested by the social group of local women.
10.3.3.2 Disability status, identity salience and guarding identity

All of the participants in this study either had an acquired disability or were close to another person who had. A degree of disability status was evident in all of the narratives. Disability status implies negative connotations and many with ABI experience stigmatisation and discrimination due to this (Levack, Kayes and Fadyl, 2010). Thus a disability status secures less status and power than a non-disability status. This in turn drives behaviour in group situations (Turner, 1971). For adults with ABI this could signal rejection by others in a group, in that their master status of disability infers differing characteristics from most group members (Becker, 1973). For example Angie (ABI: P3) expressed dismay at not being able to secure friendships outside of groups with disabilities. Indeed discrepancy can result between the person with ABI’s self-concept and the social categorisation by others, described as, ‘loss of self in the eyes of others’ (Nochi, 1998b, p873). The validity of the self-concept can be denied, obscure individuality and a negative label applied to them. Individuals with ABI may feel at a loss in the way they present to other people and fear being singled out in social situations too (Robison et al., 2009). Some cognitive disabilities of ABI can remain relatively well hidden to strangers and a decision is sometimes made in social situations as to whether to disclose or not, with fear of being stigmatised or defined uni-dimensionally. Angie guarded this disclosure carefully, especially at work. A struggle to control the perception of others and maintain a positive self-concept has been found in other studies besides this one (Olney and Kim, 2001).

So how does the individual maintain coherence in their self-concept within the milieu of competing social identities, especially now they live with ABI or they hold a role as a significant other of someone with ABI? This is where the idea of a salience of identities comes in. Different identities are activated at different times, depending on the social group at any point in time. Its purpose is to achieve certain personal and social goals for the individual by coming to the fore (Stets and Burke, 2000). A situational variability takes place depending on the stimuli to self-categorise, thus different social identities emerge at different times. The individual cognitively renegotiates their frame of reference in any situation, so as they have the most positive self-concept in that situation (Hogg, Terry and White, 1995). For example, being a worker may not hold the same significance post-brain injury as it did prior (Johansson and Tham, 2006), or the participant who was an engineer pre-injury may use the new identity of advocate and volunteer to have salience post-injury.
(Christopher, ABI: P8), in order to help manage significant losses (Gelech and Desjardins, 2011). Furthermore hiding cognitive deficits in certain public situations may seem like a necessity for some (Angie, ABI: P3), yet in the social situation with others with similar disabilities e.g. connected to one of the brain injury charities, pronouncement of deficits is acceptable. Angie closely guarded her disability status from work colleagues, but highly valued the chance to share with a friend who experienced the prosopagnosia like herself.

What this study revealed, similarly to other studies, is that there is resistance by people affected by ABI to the typical passive identity positioning by others not affected by ABI (including within healthcare interactions) and the negative labels assigned by others (Nochi, 1998; Cloute, Mitchell & Yates, 2008). Furthermore, the identity post-ABI is multiple and moves beyond the primary ABI-identity to bring forward partial past identities, such as those from professional groups, as well as establishing new identities (Lorenz, 2010; Gelech & Desjardins, 2011). Indeed, it may be that pre-ABI identities are sustained because individuals experience a subjective personal sameness which serves to protect self-continuity, avoiding acknowledgement of how much life has changed (Medved & Brockmeier, 2008).

10.3.4 Social capital, infrastructure and support

10.3.4.1 Social capital

Attention turns to means of support for the participants. Firstly, social capital was a means of support for almost all participants in the study. It is comprised of the affiliations and networks at one’s disposal, likened to the resources one has, in order to be a player on a social field (Bourdieu, 1977). This analogy of a field, with a game played on it, can be contextualised for people whose lives are impacted by ABI in that how successfully they manage their lives post-ABI will depend on the quality of the affiliations and networks they have to support them. This would be the same for both those with ABI and significant others, as the social field would have become unfamiliar territory when biographical disruption occurred. Indeed Bourdieu discussed the issue of social capital not being a level playing field: people are on the field with differing levels of capital and change occurs whilst on the field (Bourdieu, 1977).
So is it not surprising that networks and affiliations will be used as a coping mechanism, bearing in mind the array of potential disruption to life post-ABI, for the person with the ABI and significant others? For the person with the ABI dealing with the symptoms, emotional and psychosocial impact alone and without support would be very difficult. Social integration and work disruption compounded by identity issues would have been difficult to navigate and likely to be unsuccessful without social support. Stress and strain in the caregiving role may be apparent, especially where the significant other is left in sole charge of their loved one and services withdraw (Mauzer & Richer, 1998; Knox, Douglas & Bigby, 2015), estimated to be present in as many as 42% of carers of people with ABI (Boycott, Yeoman & Vesey, 2013).

The social capital drawn on by participants in this study was in the form of family, friends, charitable organisations, paid carers and social groups such as sports organisations, with limited access to ongoing statutory services for long-term support. Charitable organisations typically offer the opportunity to meet up with people in local communities in similar situations and share ways of coping, very effectively in circumstances of long-term conditions such as ABI (Cobb, 1976; Ergh, Rapport, Coleman & Hanks, 2002; Butera-Prinzi et al., 2010). Social support from families following ABI has been reported to be crucial and impact significantly on quality of life and can even bring families closer together by having a shared optimism, at the same time as acknowledging grief (Gould & Ponsford, 2015).

Interestingly this phenomenon of social capital and its impact in supporting people impacted by ABI is not always conceptualised as a significant factor by health professionals. One recent healthcare study looked at community support care hours required for people with traumatic brain injury and based observations on functional skills, including behaviour disorder of the individual with brain injury, with little acknowledgement of ongoing community support such as families, friends or charities (Clark-Wilson et al., 2016). This suggests that the medical model continues to diminish the important role of social capital and a paternalistic viewpoint that professional healthcare input, even long-term, is the key-determining factor in living a successful life post-ABI. A re-consideration has been called for in terms of which outcome measures are utilised in healthcare research to evaluate the recovery experience, promoting the inclusion of factors such as reconnection with life and identity following ABI (Levack, Kayes & Fadyl, 2010) and for healthcare professionals to pay attention to support needs of significant others too (Jumisko,
Lexell & Soderberg, 2007a). A strong or weak base of social capital will impact significantly on the recovery experience and should therefore be acknowledged.

Although most of the participants in this study discussed the social support they did receive, in terms of spouses, charities, family or friends, it was apparent that there had been a decline in social capital from the social circle of friends and family too. This might be explained from the perspective of social identity issues, as discussed earlier, but may also be due to such as others not understanding the issues associated with ABI and some of the challenges and behavioural issues that may result. Some very practical reasons may contribute to this too, for example environmental barriers to be able to access the same public and private spaces, such as the house of a relative having steps that a wheelchair is unable to navigate. One male significant other (Doug, SO: P9) found himself primarily in the female company of his wife’s paid carers and longed for male company as a social outlet: other males were only around for socialising in the evenings when he needed to be at home to settle his wife to sleep.

Being able to participate in competitive sport requires an investment of infrastructure, which appears to be lacking for disability sports, in this study it being sailing for Christopher (ABI: P8). Participation could be facilitated by accessible venues and access to adapted equipment, so as engagement can take place on a competitive level so as people with disabilities can gain the same kind of health and wellbeing benefits from participation. Sport England has been investing in disability sports since 2012, acknowledging that over 1.5 million disabled people in England play sport every week. Furthermore they encourage the use of disabled persons’ personal budgets to access sport too (Sport England, 2016). However, closer inspection of where their finances have been invested reveals that this tends to be concentrated in areas of higher populations, as one might expect, making access difficult if living in rural areas associated with this study.

So in terms of this study, what kind of statutory support was being accessed, and where it had been accessed over the course of the ABI experience, and how did it contribute to the social capital for the individuals? Firstly, acknowledgement needs to be given to the welfare benefit system, which seemed to have the most impact on the two single participants with ABI, of working age, who lived alone in social housing. At the time of the interviews a system of welfare reform was taking place, by way of the Welfare Reform Act, 2012 (HMSO, 2012), which not only made...
finances more restrictive and complex for the participants, but by virtue of living with
cognitive issues, the communication with welfare employees, who typically had little
understanding of ABI issues, was hampered. This was a source of frustration and
anxiety for both the present and potentially the future, as both finances and housing
were not secure, (especially for one participant who had spent a number of years in
her forties living in a home for older people with dementia, due to lack of suitable
residential facilities and having lost her private house due to a relationship
breakdown).

Infrastructure in terms of availability of respite care was also an issue for some
significant others. Whilst one significant other was unable to access this due its
scarcity (Rita, SO: P12), another (Doug, SO: P9) refused to contemplate this
(although a need was strongly expressed) due to his caring urge, coupled with fear
of the respite care not being of sufficient quality; his wife’s health issues began with
mistakes being made in statutory services, with further instances.

10.3.4.2 Health services

All of the participants had mixed experiences of provision of health services, with
varying instances of good or even excellent practice. However, all discussed poor
experiences too. Even when medical stability had been reached there was a
predominant culture of medical model services at the rehabilitation stage and long
term. Furthermore some expressed a feeling of being left to fend for themselves
after the stage of medical stability, when they felt far from being ready to do so and
not knowing how to cope with after effects of the ABI (Angie, ABI: P3; Hilary, ABI:
P6; Christopher, ABI: P8; Doug, SO: P9). So what is the predominant model of
healthcare for ABI services in the UK, is it predominantly a medical model and is this
policy driven or a mere consequence of the structure of the UK health services?

The national clinical guidelines for ABI are published by dominant medical
organisations: The British Society of Rehabilitation Medicine and The Royal College
of Physicians (BSRM&RCP, 2003). Accompanying this document is the National
Service Framework (NSF) for Long-term Conditions, published by the Department of
Health (DOH, 2005). Underpinning evidence for these documents was drawn from a
variety of sources, such as published research to support ABI interventions and
identified experts in the field, predominantly following the established biomedical
hierarchy of evidence. These sources place an emphasis on RCTs and systematic
reviews of quantitative research (Concato, Shah & Horwitz, 2000), although service users from a working party were included. Current UK health and social care policy has a market-orientated approach drawing on research from measurable criteria (Laver Fawcett, 2007). In the documents recognition is given to a need for a variety of professions for rehabilitation and support services and that the effects of ABI are often for life, advocating a need for continued care (BSRM&RCP, 2003). The process of developing such guidelines can be described as rigorous, but arguably is very clinically focused. The heterogeneity in ABI symptoms and thus lived lives is identified, yet this acknowledgement does not seem to be considered as a contributing factor to the lack of consistency in being able to quantify the success / lack of success of interventions. Below is an excerpt from the concluding section of the document where outcomes for ABI services are discussed:

"Meta-analysis and other assimilations of rehabilitation outcome data are frequently confounded by the lack of consistency in outcome measurement. A number of well-validated generic tools are now in existence. Whilst no single outcome measure is suited to all circumstances, it may be appropriate to choose at least one or two global outcome measures, both for research and routine clinical services, which over time will provide a common dataset."

BSRM&RCP, 2003, p56.

This suggests that despite the wide ranging and complexity of symptoms of ABI the measurement of rehabilitation success is anticipated as being reducible to one or two outcome measures i.e. a reductionist and medical model approach. It is suggested in this thesis, due to complexity and heterogeneity of ABI symptoms, as well as the variety in personal circumstances of individuals, that this may not be achievable unless the outcomes of rehabilitation remain focused on biomedical symptoms. Furthermore, specific ABI guidance from the College of Occupational Therapists’ Specialist Section in Neurological Practice (COTSSNP) is available, mapped directly against the two health documents mentioned above (COT, 2013). This document is promoted as the guide for occupational therapists working with people with ABI. By virtue of it directly mapping to the biomedical documents it could be argued that it too has predominantly a biomedical or physical health focus. However, UK occupational therapy education covers both physical and mental health assessment and intervention. Indeed the Standards of Proficiency to practise as an occupational therapist in the UK require them to:

'know how to meet social, psychological and physical health-based occupational needs of service users across a range of practice areas’

HCPC, 2013, p15.
However in the realities of practice, employment opportunities tend to focus occupational therapists to work within singular divisions of healthcare services, that is, either in physical healthcare or mental healthcare, but rarely both. This is despite claims of holistic practice:

‘Occupational therapy takes a whole-person approach to both mental and physical health and wellbeing, enabling individuals to achieve their full potential.’

College of Occupational Therapists, 2016.

This would explain why the COTSSNP document remains aligned to the biomedical or physical health focus. Elsewhere however, the use of narratives is recommended in the ABI clinical setting (Eschenfelder, 2005; Preston & Edmans, 2016).

The long-term impact of ABI is identified in the BSRM&RCP document, but little guidance on how long-term rehabilitation support should be approached. In contrast the NSF document is much more explicit that long-term support for both those with ABI and carers and refers to emotional support and addressing such as self-image (DOH, 2005). Self-image is arguably an alternative way of phrasing identity. However how to address it is lacking.

The COTSSNP document with its biomedical focus aside, are there any occupational therapy assessment tools currently available to consider, that draw on the occupational theoretical concepts of the Profession, such doing, being, belonging and becoming, and any cultural capital accumulated? And if so, do they have the potential to address issues of occupation, narrative and identity, as opposed to reverting to the biomedical measurement of function and its drive to be able to demonstrate effectiveness in a market-approach to health and social care?

And are any such tools currently being utilised by occupational therapists in the field of ABI to address the self-discrepancy between pre- and post-brain injury identity to ‘provide resources to figure out who they are’? (Frank, 2010, p71; Bryson-Campbell et al., 2013; Nalder, Fleming, Cornwell, Shields & Foster, 2013). In the situation of ABI this would be approached in terms of moving forward in life, as opposed to the aim of remediation to ‘normal’ and previous status (Conneeley, 2012). Taking part in occupation for those with ABI has been identified as key to this process (Erikson, Karlsson, Borell & Tham, 2007; Gracey et al., 2008; Hoogerdijk, Runge & Haugboelle, 2011).
Such theoretical concepts are indeed the underpinning of the Model of Human Occupation, from which a number of occupational therapy assessment tools are derived. This occupation-focused model purports to be both holistic and client-centred (Kielhofner, 2008). Within its battery of assessment tools, one does address life history and occupational identity: the Occupational Performance History Interview – Second Version (OPHI-II) (Kielhofner et al., 2004). This tool has been used in a variety of occupational therapy practice and research settings: to understand the relationship between occupation and identity (Braveman & Helfrich, 2001; Braveman, Kielhofner, Albracht & Helfrich, 2006); to measure changes in occupational performance (Verhoef, Roebroeck, van Schaardenburgh, Floothuis & Miedema, 2014); to gather narratives to understand experience (Gray & Fossey, 2003; O’Donohue & McKay, 2012; Sandell, Kjellberg & Taylor, 2013); to draw out narrative metaphor (Mallinson, Kielhofner & Mattingly, 1996); to set goals for practice interventions (Apte); to understand role transitions (Levin & Helfrich, 2004; Hamilton & de Jonge, 2010); and, to understand people on their recovery journeys (Ennals & Fossey, 2009). Service user perceptions of the OPHI-II were that it allowed personal insights and reflections on circumstances, which influenced their view of the future (Apte, Kielhofner, Paul-Ward & Braveman, 2005).

10.3.5 Rural issues

One of the purposes of this study was to explore if and how the rural location influenced the post-ABI experience and engagement in occupations. This was potentially both in terms of social and economic factors, such as access to healthcare services, work opportunities and transport, and the embodiment of the rural geography and alignment to the rural community. However, no persistent themes emerged from the data, although rural living did impact on individual circumstances of some participants.

Access to services was a clear barrier to engagement in occupations for one participant (Rita, SO: P12), who had moved to a rural area, in that health and social care staff lacked specialist knowledge of ABI and she had to address this herself with charity support. Challenges to accessing services in the community have been reported elsewhere (Health Development Agency, 2004). Yet another participant, Doug (SO: P9), moved with his wife from an urban area that was poorly serviced to a different, quite remote rural area in order to access better services and strongly
advocated this due to the significantly better specialist ABI services. Whilst it is generally held that a postcode lottery may exist with respect to provision of ABI medical and healthcare services, evidence to substantiate this, with specifics of where and how variation exists is lacking (National Audit Office, 2010b; RCP/BSRM, 2010; Hawe, Baillie & Schaffer, 2013). However, it is known that only one fifth of joint health and wellbeing strategies in the UK made reference to neurology in 2015, despite is being recommended to be by clinical commissioning groups in 2011 (National Audit Office, 2015). This would indicate a significant shortfall in ABI services nationally.

Lack of regular public transport was an issue for those who wanted to access activities in local towns or cities, such as potential work opportunities or social opportunities, though most participants had access to personal transport means, or public transport worked well for them: again, individual circumstance differed considerably. Furthermore, individual variation was seen with respect to the social space of the rural setting, with one participant not finding enough social outlets, whilst two participants with cognitive deficits appreciated the peace and quiet of the countryside, especially due to their sensory hyperacuia. This would suggest that there may be benefits in particular individual circumstances to the reduced stimulation of the rural setting, with less people, less noise and a quieter approach to life. A participant with prosopagnosia had experienced embarrassment at not recognising people she had known for a long time, whilst living in an urban environment: the move to a small village had meant that there were less people to not recognise, saving embarrassment; and some villagers were aware and understanding of her situation. Embodiment of the rural environment, in terms of it being physically pleasing was acknowledged by some, but not mentioned by others, as one might expect in the general population.

In summary, with respect to the rural setting impacting on people affected by ABI and engagement in occupations, each individual participant had a story to tell, with personal and regional variations, including the availability of statutory services.

10.4 An occupational persistence

With the main focus of the study being on occupations within the narratives of people affected by ABI, attention now specifically turns to this. So, what does the
telling of the narrative reveal about how people construct new occupational relationships with their post-ABI worlds and how is their engagement in occupations and roles constructed in the narrative? The major finding from this study was how participants persistently held on to their past occupational identities following their life being affected by ABI, be it as the person with the ABI or as a significant other. This highlights the inter-connectedness of occupation, narrative and identity. Whilst participants in this study drew on social capital for support as discussed earlier, another of Bourdieu’s concepts of capital is worthy of further discussion, in order to explain this relationship within the findings of this study.

10.4.1 Cultural capital, habitus and cognitive schema

Bourdieu discusses the idea of different types of capital being at play in ‘the field’, those being economic and cultural forms of capital, besides social capital (Bourdieu, 1986, p243). Cultural capital is of interest in relation to this study, with respect to its embodied state and resulting habitus, associated with the habits and roles of the participants.

According to Bourdieu, by working in a particular field, accompanied by assimilation from aspects of that field, a cultivation of an embodied state results: the mind and body adapt to a specialised field or habitat, (defined specifically by Bourdieu as habitus). Habitus allows an effortless approach to understanding the field in which one finds oneself, or the ‘rules of the game’. The outer social, becomes the inner, second nature (Bourdieu, 1984, p71). For example, the engineer becomes the embodiment of engineering (Christopher, ABI: P8), with cognitive structures aligned to the field of engineering. Whilst this cultural capital can be assimilated as a result of education, it can also be acquired unconsciously, if subjected to the conditions of acquisition (Bourdieu, 2008). For example, the habitus may relate to this as a profession or a particular social class, way of speaking etc., but it is embodied.

Bourdieu discusses the role education plays in establishing part of the cultural capital. The type of educational opportunities and the opportunity for further educational opportunities can contribute to this. So might other theories, such as developmental learning theories, contribute to the embodying of occupations that were revealed in the narratives in this study of daily life affected by ABI? Developmental learning from an interactionist viewpoint proposes that children’s cognitive development is a result of their interaction with the environment and
subsequent inquiry, allowing them to construct and organise their mental development (Wadsworth, 2004). Mental representations of the world or schema develop, relating to aspects of the world. They increase in complexity over the course of development allowing the individual to both generalise and differentiate as they age (Piaget, 1952). In order to complete a task, the child develops more sophisticated skills than simply acting to accomplish a goal and also draws on indirect methods, such as development through intrapersonal speech to plan how to act. Vygotsky (1978) argued that through the course of memory and perception development, more sophisticated ways in which to act become available with the social context having a significant part to play. The zone of proximal development becomes the space between where an individual can problem solve alone and problem solve with the help of another (Vygotsky, 1978, p86). Participants in this study had been exposed to occupational environments, and subsequent schema associated with the memories and perceptions of those environments would have developed.

Cognitive schema theory is a theory of information processing, whereby the memory stores learned schema, which can be called on and activated should immediate action require it. The schema may further build to form mental models, which can be drawn on for problem solving in similar situations. It is suggested that if an individual is presented with a situation that is difficult to comprehend, they refer to past cognitive resources to make sense of things (Derry, 1996). These contribute to the cultural capital.

So in what way is Bourdieu’s cultural capital relevant to the findings from this study and in what way might habitus have a bearing on how participants whose lives were affected by ABI, narrated their story? And how are schematic representations relevant? In this research with people affected by ABI, participants had been through a process of normal child development and been educated and worked to various degrees. Their schematic development will have been both influenced by the socio-cultural environment, educational and work experiences (i.e. habitus). Of specific interest to this study is the schema that will have developed as a result of engagement in occupations. It could be argued that participants drew on past occupational schema to make sense of the complex world of life with ABI they now found themselves in, in some cases discussing what appears to be a mental model of the schema to frame their current situation. For example, the engineer who now saw his life as an engineering project (Christopher, ABI: P8) and the nurse who put
on her ‘nurses hat’ (Helen, SO: P7) as this was the resource they were most familiar with, to deal with a new complex situation. An occupational persistence, linked to the occupational identity, was observed through three elements: the narrative discourse; the types of occupations still engaged in post ABI; and in some cases how individuals framed their lives.

It would appear that both those with ABI and significant others are drawing on their habitus, of interest in this study that being their habitus of past occupations, to select occupations to engage in as part of their occupational repertoire. What is of further interest is the way in which the cognitive structures of the habitus were utilised as a ‘taken for granted’ way of framing daily life and coping. For example Rita (SO: P12) began to frame intervening in the behaviour of her husband like a special educational needs teacher; Doug (SO: P9) although retired from a career in human resources and finance spent most of his day organising the staff who deliver his wife’s home rehabilitation package; and Bruce (ABI: P4), who even though he had significant residual brain damage and was no longer a policeman, still engaged in community service by giving excess produce to others.

This would suggest that Bourdieu’s cultural capital in this circumstance is specifically of interest with respect to occupations, embodied by the individual in the occupational identity, built up from time spent in the occupational field and becoming familiar with the rules of the game of that occupation. Capital has been assimilated by way of the development of the cognitive structures of the occupation. It may be that the individual is pre-disposed to the skills required for the occupational field and has developed those skills, according to processes of developmental learning theory and acting in the zone of proximal development (Vygotsky, 1978).

In this study with individuals whose lives were affected by ABI, an occupational persistence was evident, whereby they drew on past occupational roles to enact aspects of those occupations in the present, even when those work occupations had not been available to them for several years. It would suggest that assimilation of the cognitive schema, capacities and skills of those occupational roles stayed with individuals for long periods of time, possibly impacted on by an associated maintenance of the occupational identity and habitus associated with the occupation. This becomes subsumed into the narrative. There is no doubt that there may be a decline due to iatrogenic effect of impairment (Cameron, Sadlo, Hart & Walker, 2016), or time spent absent from the field due to biographical disruption,
leaving the participants in an unequal field, especially if they wished to still work. But it must not be forgotten that it has already been suggested that there is reluctance by those with ABI to leave behind the pre-injury identity (Heller, Mukherjee, Levin & Reis, 2006; Gracey et al., 2008; Muenchberger, Kendall & Neal, 2008; Carroll & Coetzer, 2011). What the outcomes of this research suggest is that there is not only a residual persistence in occupational identity, but a persistence in occupational habitus too, due to cultural capital being retained to some extent. In this research it acted as a resource for daily living, whereby there was persistence in the occupations engaged in, or whereby the cognitive schema of the occupation framed other aspects of their lives. Bourdieu talks of the habitus being:

‘The system of dispositions – a past which survives in the present and tends to perpetuate itself into the future by making itself present in practices structured according to its principles’

Bourdieu, 1977, p82.

In the situation of this study, the individuals drew on their past occupational habitus to perpetuate aspects of those occupations in the present. This left individuals with an embodied occupational potential or capital, which could perhaps be exploited in therapeutic settings for moving forward in life post-ABI.

10.4.2 Occupational capital and embodied occupational identity

A similar idea of occupational capital has been proposed elsewhere (Cameron, Sadlo, Hart & Walker, 2016). But does this past-published research fit with what is being proposed here in this study? Cameron, Sadlo, Hart & Walker’s idea of occupational capital was first published with respect to people with mental health problems requiring support in order to return to work. They propose occupational capital comprises of accessible work opportunities, support in order to participate in work, coupled with internal capacities of the individual, such as skills. Furthermore they suggest that the iatrogenic effects of mental ill health serve to reduce the occupational capital of the individual with mental health problems (Cameron, Sadlo, Hart & Walker, 2016, p281).

Whilst it is pleasing to see the integration of Bourdieu’s significant ideas into occupational science / therapy theory and research, the limited explanation offered in their publication could be enhanced with further consideration of their ideas. In the article they link occupational capital to social capital, yet include the internal capacity
of the individual: Bourdieu describes social capital as being more aligned to external networks and group membership, with enacted and exchanged relationships as a potential resource (Bourdieu, 1986). The internal capacity of the individual that they mention is more aligned to Bourdieu’s cultural capital, which is not discussed in their article. It could be argued that their definition, with respect to the internal capacities, does not go far enough and has overlooked Bourdieu’s idea of the cultural capital being embodied and cognitive structures being part of the habitus that results (Bourdieu, 1986). What is being proposed in this study is an alternative explanation of occupational capital, whereby the occupation is an embodied state: occupations have been assimilated through the individual being exposed to the occupational field, resulting in cognitive structures and a familiarity with the habitus of that occupational field. The experience of the occupation extrinsically weaves together the individual and the context in which it takes place (Dewey, 1938). The extrinsic social capital of networks and affiliations will also contribute to the individual’s occupational capital too.

What this 2016 article, applied to mental ill health, suggests about occupational capital is very similar to the proposal of occupational potential, described as ‘a person’s capacity to do’, based on an expansion of Wilcock’s prior work (Wicks, 2014, p221; Wilcock, 1993). Although Wicks does not refer to Bourdieu’s ideas of various forms of capital she describes some very similar phenomena, such as how occupational potential develops over time, through experience of social, cultural and political environments and being over and above personal attributes and external resources. Realisation of occupational potential is something that is harnessed when occupational adaptation is required (Wicks 2014). In this study occupational adaptation was required following ABI, when participants’ previous occupations were interrupted. Wicks’ article thus goes further than that of Cameron, Sadlo, Hart & Walker and suggests an embodiment of capital, similar to Bourdieu’s cultural capital, although not expressed in Bourdieu’s terms.

For Cameron, Sadlo, Hart & Walker to propose a new form of capital occupational capital is a bold move, but it can perhaps be explained as a combination of social and cultural capital with respect to the individual’s occupation. Furthermore, they omit the embodied aspect of the occupation, in terms of the cognitive structures assimilated from the habitus of that occupation in their definition. It is suggested here that rather than occupational capital being a new concept that it may be a combination of social and cultural capital, and be already defined as occupational capital.
potential. Incorporation of Bourdieu’s concepts of *habitus* and *field* into the concept would justify this, the *habitus* being ‘systems of durable, transposable dispositions’ (Bourdieu, 1977, p72) or an individual’s ‘history turned into nature’ (Bourdieu, 1977, p78). Then the iatrogenic effects of illness on gaining employment in their study may be explained by ill health and absence from the workplace, reducing the embodied aspects of the occupation, as well as time spent away from the social field. That is to say, an absence from the field or occupation’s habitus for a period of time whilst ill, may indeed result in an unequal field for gaining employment. This would be especially so when coupled with the symbolic aspect of cultural capital for people with, in their research, mental health problems, due to associated stigma (Goffman, 1963; Bourdieu, 1986; Cameron, Sadlo, Hart & Walker, 2016). However, this research found that the embodied aspects of cognitive schema and perception, associated with past occupations, persisted to some degree: both those with ABI and significant others drew on it to adapt to occupations in daily life, even in those who had not worked for a significant number of years. It was utilised in the zone of proximal development (Vygotsky, 1978).

In summary, this is to say that if there is such a phenomenon as *occupational capital* it is capital with a focus on the occupational aspects of the two already defined terms of *social capital* and *cultural capital* and what must not be forgotten is the aspect of the occupation being an *embodied occupational identity*, through not only skills and capacities, but cognitive schema (Bourdieu, 1986). Pursuit of the occupations is closely associated with identity (Christiansen, 1999; Christiansen, 2000) and the individual’s occupational potential (Wicks, 2014). This fits with the concept of *doing, being, belonging and becoming* (Wilcock & Hocking, 2015). Where those affected by ABI continued to *do* they continued to *be*, by holding on to the past occupational identity, as this was a key tool in their zone of proximal development.

### 10.5 Occupational therapy intervention: utilisation of the embodied occupational identity

This study had a focus on *occupation* for those affected by ABI, living in rural areas and the underpinning theory of the link between *occupation, identity* and *narrative*. So is there more specific guidance relating to occupation and occupational therapy interventions following ABI and if so how closely aligned is this guidance to the
concepts of *occupation, identity* and *narrative*? The specific ABI guidance from the College of Occupational Therapists’ Specialist Section in Neurological Practice (COTSSNP) is available, mapped directly against the two medical documents mentioned in Chapter 10 (COT, 2013). Whilst it is acknowledged that this is extremely useful guidance for occupational therapists to work clinically with service users with ABI, the focus remains predominantly bio-medical and fails to draw on the Profession’s own philosophical roots with respect to the place of occupation in people’s lives and principles such as *doing, being, belonging* and *becoming* (Wilcock & Hocking 2015) or the link between *occupation and identity* (Christiansen, 2000).

Furthermore, whilst the COTSSNP document claims to draw from the NSF document which mentions self-image i.e. identity, there is no guidance on how occupational therapists should address this issue, other than through it being implicit through improving function. Whilst the COTSSNP document is overt in placing its purpose as being to map against the bio-medical guidelines, the overall presentation of the guide, with its Professional Body endorsement, would suggest that it is *the* definitive guide for occupational therapists working with people with ABI. However, it omits the key facets of *occupation and identity*. The occupational aspects of the document are addressed in terms of function, such as daily living tasks, leisure, vocation and driving.

The reason for the Professional Body publishing a document more aligned to a bio-medical approach than its own occupation-focused philosophical roots may be so as to remain as a participant in the clinical rehabilitation team and thus the need to utilise the accepted discourse of that team. However, in doing so it may be overlooking potential key contributions that the Profession could make to individuals with ABI and their significant others that are more occupationally-focused.

So if the key occupational therapy document is more aligned to a bio-medical approach and functional outcomes for people with ABI, how, if at all, does it address the emotional or psychological aspects or is this not an issue for occupational therapists? In order to address this point consideration turns first to the COTSSNP document and then to the areas of practice for occupational therapists in general. The COTSSNP document contains a total of 87 points for occupational therapists to consider when working with people with ABI. Only one makes reference to psychological issues. Point 67 asks:
Do I know how to contribute to assessment and management of mood and when to refer for more specialist intervention, e.g. psychological therapy?

COT, 2014, p45.

This suggests that psychological issues such as depression or anxiety are not a key focus for occupational therapists working with people with ABI to become involved with in rehabilitation. What appears to happen is that the therapist follows the specialist remit of the rehabilitation team they are placed in, leaving psychological issues to the clinical psychologist in the physical field. This leaves a gap in terms of the occupational aspects from a psychological perspective, when ABI services are firmly placed within physical healthcare services and occupational therapy services are more directed towards function. An individual with ABI may receive mental health services addressing occupation if they are referred into them additionally, due to such as anxiety or depression, but such services in the mental health field will not be specialised for addressing some of the core identity issues which may be part of the root cause of this for those affected by ABI.

Taking the COTSSNP guide as a mapping exercise against the bio-medical BSRM&RCP document, rather than occupational intervention with ABI in totality, then are the occupational aspects of therapy, linked to the theory base of doing, being, belonging and becoming, promoted elsewhere by occupational therapists for this service user group? Indeed COTSSNP does advocate occupation as a concept at the Profession’s roots but acknowledges the complexity of converting this into practice. The use of narratives is recommended to fully explore life roles, activities and experiences in the clinical setting (Eschenfelder, 2005; Preston & Edmans, 2016). However, when attention then turns to which tools to measure the impact of intervention, recommendations become more task, function and performance orientated. This leaves a gap between gathering narratives of people affected by ABI in practice and then using narrative as a practice intervention. In other words, the narrative, occupation and identity connection is not being utilised with a service user group where identity issues have been found to be key in moving forward in rehabilitation (Heller, Mukherjee, Levin & Reis, 2006; Muenchberger, Kendall & Neal, 2008; Carroll & Coetzer, 2011).

This prioritisation of function over occupation can be explained by UK health and social care policy, and its market-orientated approach driving evidence-based practice; a strong requirement for well-defined, measurable outcomes of practice.
exists (Laver Fawcett, 2007). Measurement of a therapy impact on identity, as an issue for biographical disruption, would be more complex and less achievable and possibly beyond the time constraints of therapists engaged in busy day-to-day practice. Thus the impact of intervention focused on narrative, identity and occupation, underpinned by the Profession’s theoretical concepts of doing, being, belonging and becoming would be less justifiable in the arena of current UK health & social services, despite attention being drawn to self-image in the NSF document.

In summary, the relationship between occupation, identity and narrative is not addressed in UK health services and may remain unresolved for many with ABI, due to ABI services being placed in the domain of physical health where there is an occupational focus on function, rather than the impact of occupation on psychological issues. Furthermore, variations in the availability of services to support people affected by ABI is an issue and where services are available the biomedical focus does not necessarily suit or meet long-term needs. However, the findings from this study present an opportunity to consider occupational therapy intervention in alternative ways and considering the embodied occupational identity of the individual.

10.6 Limitations

This study involved locating interested participants and researching their experience of ABI. It employed a lightly structured interview technique, combined with photo-elicitation, to generate a narrative. The interviews of the twelve participants were then subjected to a narrative analysis, resulting in twelve highly individual stories. It should be borne in mind that this was a constructivist approach to research, in that the narrative was a form of social accomplishment for the narrator, influenced by the presence of this particular researcher as interviewer and her position as interpreter (Crotty, 1998; Dyson & Brown, 2006).

Each significant other had their own narrated experience of ABI and how it had impacted on their own life: it was not a vicarious voice of how the narrative had changed for their loved one following their ABI. Each participant with ABI narrated their own experience too, regardless of any cognitive impairment. So why was this important and how did the research approach come close to revealing the actual reality of the lived lives of the participants? Indeed it was important to hear
autobiographical accounts in this research: the connection between narrative and identity had been highlighted and if the research had not been autobiographical, the data would have revealed identities constructed by others (Hydén, 2008). Of further significance however, is that the researcher was undertaking the process of narrative analysis and potentially structuring the stories from her own stock of reality, both interpersonal and social, emerging from the fact that human beings cannot have the same experiences (Harré, 1983).

The research interview was a different approach to the naturalistic setting of a conversation and to an extent the narrative could be critiqued as obscuring life as actually lived (Elliott, 2005). However, the single question aimed at inducing narrative approach (SQUIN) empowered participants to select what elements of their lives they wished to reveal as opposed to being researcher-led and more directive to issues assumed by the researcher (Wengraf, 2001). This allowed as far as possible for participants to tell the important elements of their own life stories.

Checks and balances employed with respect to this. Chapter 6 discusses the engagement with the researcher’s positionality, reflexive diary-keeping, careful reviewing of video data, attention to detail in the transcription process, returning analysed stories to three of the twelve participants and an independent analysis with the director of studies. A final reflexive excerpt is offered below, highlighting some examples of how the researcher may have impacted on the study and vice versa:

“I am a registered health professional working in education and with healthcare experience, which will have impacted on the study. As a member of my Professional Body, with the professional identity of an occupational therapist, there may have been a tendency to be protective or defensive of any criticism of my profession during the research. This issue was certainly presented in one interview, with Angie, who talked about being unable to fulfill her dream of becoming an occupational therapist, because the practice placements on her degree programme would not make adjustments for her own disability of facial blindness and she was asked to leave. I have been, in the past, in the uncomfortable position of discussing with students their failure on placement, where there is a fine line between adjustment for disabilities and lack of competence. Instead of becoming defensive with Angie I became slightly embarrassed, now that I listened without interruption.

This in itself could produce a different issue, whereby with participants opening up their personal feelings to me, and me coming from a caring background, it may have influenced me wanting to present participants in a positive light, especially if they were going to read their stories at some point in the future. I have, however, found it very helpful to discuss the stories with my supervisor and colleagues, as sometimes they offered an alternative perspective. For example, my sister was employed as the professional transcriber and she would make comment on the stories when they were returned to me, sometimes quite different to my own views and this would make me reflect on what might have been taking place during the interview, such as
transference, or other interactive behaviours. I did not always pick these up during the interviews, but was able to reflect on these watching the video recordings at a later stage.

A further reflexive point to note is how I, as researcher, was impacted by the study. This has been an in-depth study over a number of years, adopting an approach that empowered people affected by ABI (either directly or indirectly as a significant other). One of the main surprises to myself was how primary identities were still presented as such as husband, wife, worker or friend: identities as ‘person with a brain injury’ or ‘carer’ were supplementary to these and not overarching (and in some cases the carer identity was rejected altogether e.g. with Doug). This has possibly influenced the way I now conduct myself as a trustee of a charity with several other trustees having neurological conditions: I like to feel that I do not dominate or see myself as anything other than equal. I am also aware in my daily life, that new people I come across carry occupational identities from their past, rather than just how they overtly present to me.”

The relativist perspective of constructivist research such as this research must be borne in mind too, in that biographical interviews typically produce a self-preserving self-presentation from the interviewee with a future audience in mind (Wengraf, 2001). And furthermore, constructivist research does not make claim to accuracy in the same way that realist research does, rather it promotes transparency in the way in which the knowledge has been constructed, through such as reflexivity, to improve the quality of the research, accepting that the hermeneutic circle may never close (Finlay, 2003).

This study does not claim to be representative of all who present in health services with ABI, or their significant others. The participants were recruited through charitable organisations associated with ABI and most had few other complicating factors in their lives which those with ABI can commonly present with, such as dual diagnoses like drug addiction and long-term mental health issues. Indeed by being individuals who were keen to take part in research it could be argued that they may have been more likely to have motivations around a manifesto for better services for those affected by ABI (Frank, 2013), or potentially be more optimistic by virtue of being keen to engage.

Bearing in mind the relativist perspective of the research, no claims are being made as the widespread utility of any potential interventions around occupation. This would need to be further researched, explored and indeed tested. The findings are presented not in terms of evidence-based practice to underpin the current climate of UK health services, but rather now an opportunity is presented to take an occupational focus that is more aligned to the occupational therapy profession’s roots and move away from primarily an emphasis on functional outcomes. The
challenge for occupational therapists to apply occupational theoretical concepts to
goals of treatment for people with ABI has already been identified (Preston &
Edmans, 2016). What the results of this study offers is the clinical reasoning behind
a narrative method, using a narrative tool such as the OPHI-II (Kielhofner et al.,
2004).

Further critical application of this research highlights the persuading of occupational
therapists in the field, to act on its findings. The research is underpinned by an
assumption that people affected by ABI live in differing social circumstances. It is
social science research as opposed to being aligned to biomedical ABI research,
more commonly utilised for evidence-based practice. Occupational therapists
working with people affected by ABI are typically employed in physical medicine
rehabilitation teams, working alongside professions with a strong biomedical focus.
Although the professional registration requirements highlight issues of identity,
psychological and occupational needs as domains of concern for occupational
therapists (HCPC, 2013), there has been a tendency in this field of practice to focus
on functional outcomes (Preston & Edmans, 2016). A limitation of this research is
the challenge presented to encourage occupational therapists to draw on their range
of professional skills in a field of practice, which is influenced by the biomedical
focus of the rehabilitation team; professional body guidelines have been developed
in alignment with the current practice setting and they hold significant influence
(COTSSNP, 2013).

10.7 Future research

The analysis of interviews in this study entailed an iterative approach, going back
and forth between the data, in order to identify the embodied occupational identity in
the participants’ narratives. The OPHI-II was identified as a possible tool to gather
narratives and understand experience. However, does the OPHI-II have the
potential when used in practice, to uncover similar phenomena? Indeed the user
manual encourages the drawing out of metaphor in order for therapists to
understand the meaning of story on the basis that the story that is narrated is the
story that the individual is seeking to live their life by (Helfrich, Kielhofner &
Mattingly, 1994; Kielhofner et al., 2004). This close reading of the narrative for
metaphor, over and above the facts and the plot, allows for phenomena to appear
that may otherwise not (Mallinson, Kielhofner & Mattingly, 1996). In this study the
occupational metaphors and themes were uncovered, which were over and above the facts about participants’ engagement in occupations. It is debatable how often this actually occurs in practice however, as only one published study, now somewhat dated and at the inception of the OPHI tool, has been published on how identifying the metaphors can be applied in practice: the metaphors identified related to momentum and entrapment in life stories (Mallinson, Kielhofner & Mattingly, 1996), as opposed to linking metaphor to occupational identity. Certainly there is no current research on using such approaches with people affected by ABI, where the direction of travel for occupational therapists has been to focus on functional outcomes (COT, 2013), as opposed to occupational identity (Christiansen, 1999), the narrative mode of cognition (Bruner, 1986) and doing, being, belonging and becoming (Wilcock & Hocking, 2015). This is despite identity issues significantly impacting on individuals following an ABI (Cloute, Mitchell & Yates, 2012; Medved & Brockmeier, 2008; Levack, Kayes & Fadyl, 2010). Future research could focus on how occupational identity issues can be addressed for individuals with ABI, possibly by considering the best tool to uncover the embodied occupational identity and then potential ways of utilising the embodied schema for moving identity issues, and thus the narrative, forward.

10.8 Recommendations for practice, policy and education

Occupational therapists work alongside more bio-medically orientated professionals in the field of ABI, which may encourage a drift to working more bio-medically and less occupationally themselves. This has been exemplified by the development of the COTSSNP guide to working with people with ABI, mapped against biomedical guidelines. The occupational perspective needs to be brought to the fore in practice also. Besides working with aspects of cognitive function and daily living function with this service user group there is potential to draw on the narrative of the individual, with its relationship to identity and occupation, for better service outcomes.

In order to achieve the above, policy and guidelines would need to be broadened at the Professional Body level i.e. Royal College of Occupational Therapists, to encompass the domains of occupation and identity through exploration of the narrative in practice, rather than the current focus on functional outcomes. Thus it is strongly recommended that the COTSSNP revise the guidelines for working with people with ABI. One way in which this may be achieved is through the researcher
speaking at their national conference, followed by publications in research journals and lobbying for change.

A second recommendation is to identify and then utilise assessment tools that would facilitate the above, (possibly through use of the already existing MOHO tools, which currently are more popular in mental health occupational therapy services). The best tool would uncover the individual’s *embodied occupational identity* to draw on embodied schema of the individual, to move forward issues of narrative and identity.

A third recommendation is to make the narratives accessible to others affected by ABI or those that will be working with people with ABI in the future, for educational purposes. This could potentially be done through charitable organisations or universities educating future healthcare professionals, having access to them for their educational programmes. Currently one such charity has obtained funding to publish three of the narratives for this purpose; they provide support for people with neurological conditions such as ABI and carers, plus teach occupational therapy and medical students.

A final, fourth recommendation is for the Professional Body to make stronger reference to the importance of the link between occupation and identity in their standards for pre-registration education. The standards are currently written as complimentary to this notion, emphasising how occupation is central to human life (COT, 2014), but also reinforcing how this links to the identity of the individual has the potential to enrich student learning and thus influence how occupational therapists work with people with ABI in the future.

**10.9 Chapter summary**

This chapter discussed the analysis of the participants’ narratives with respect to the two modes of cognition (Bruner, 1986): the narrative mode producing the emplotted stories and the paradigmatic mode producing an overall theme of occupational persistence. The narratives have the potential to be utilised in a number of settings connected with ABI, to broaden people’s understanding of how life is impacted by it. Symptoms of ABI impacting on occupational engagement were discussed as well as how the ABI had enabled some in a way that may not have been expected. The chapter progressed by raising issues of how lives were impacted by identity issues.
and the forms of support that were available to draw on in daily life, in their rural setting. Current health service provision was discussed with its strong leaning towards biomedical aspects of ABI, with little mention of identity issues. The major finding of *occupational persistence* was discussed and how this may be due to the cultural capital, habitus and cognitive schema of the individuals that had developed during their lives. The current idea of *occupational capital* was critiqued and the concept of *embodied occupational identity* was coined with the idea of being a key tool for those affected by ABI to draw on as a resource for daily living. Potential occupational therapy interventions and future research are proposed.
Chapter 11  Conclusion

11.1 Introduction to the chapter

“And we sat down, erm, erm, we worked it all out ourselves and thought well why
can’t people that are trained think the same as us. You had a lad of 23, who had
everything going for him, manager of one of the biggest poultry units in the country.
All this is taken away from him and he’s left with nothing.”

This is how one participant, Diana, described how she was left feeling when health
care provision failed to recognise some of the issues in occupational engagement
for her son, several years after, but resulting from, his ABI. He had long-term follow
up appointments with the ABI services, but the focus was on being bio-medically
stable and physical health symptoms, as opposed to acknowledgement of his
psychological issues and being able to access mental health services for
intervention for his depression. This is an illustration of a gap in provision when
individuals with ABI are able to access provision located in physical health settings
but psychological issues, significantly impacting on daily life, are not addressed.

This chapter draws together the findings and discussion from this study, which had
the research aims: to explore the narrated experience of daily life and engagement
in occupations, of people living in the social context of a rural location, post ABI; to
explore the narrated experience for both those with ABI and significant others
affected by their social relationship to a person with ABI. The research purpose was
to investigate:

- what the telling of the narrative reveals about how people construct new
  occupational relationships with their post-ABI worlds
- how engagement in occupations and roles is constructed in the narrative
- if and how the social context of a rural location has an influence on the
  post-ABI experience

The chapter summaries the above and brings a ‘resolution’ to the thesis as a three-
act structure.

11.2 Narrative form

The twelve narratives of people whose lives were affected by ABI were highly
individual in the way in which it affected them and their subsequent occupational
engagement. The residual disability issues for those with ABI were numerous and varied, which is quite typical (BSRM&RCP, 2003) and thus the impact on the narratives was varied too. Furthermore, individual narratives would have developed according to their situated psychological and sociological factors (Murray, 2015).

In terms of the socio-cultural environment the rural location did not particularly reveal any generalised benefits or disadvantages to this particular group of people. The quality of services was variable in the different rural locations and what appeared to be key was if people had transport to reach required services and facilities, either by having a car in the family or public transport. The tranquility was beneficial where the brain injury left the individual with increased sensitivity to noise. Being known in the rural location and having residual symptoms understood by the community helped with acceptance for some, but where they were not understood, it induced labeling and stigmatisation.

These narratives of individuals affected by ABI offered a range of narrative typologies, according to Frank’s narrative genres of quest, chaos and restitution (1995). Not all easily fitted with Frank’s established typologies and indeed he calls for additional typologies to be considered and that any narrative may have elements of each (2010). Whilst each narrative could potentially be assigned a literary genre label that contained some form of tragedy (Frye, 1957), it is perhaps not helpful to apply any such simplistic labeling: doing so may bring further negative assumptions about the lives of those affected by ABI and promote stigmatisation. Despite a major unanticipated disruption to the biography of the participants, several continued to apply an optimistic narrative tone, which is asynchronous with tragedy. This could be a helpful note to healthcare professionals who may assume such disruption has overarching negative connotations.

The telling of the narrative revealed how people construct new occupational relationships with their post-ABI worlds in that they held on to past occupational identities. Within the narratives of the twelve participants the discourse constituted more than the words or sentences spoken within them (Polkinghorne, 1988). When an analysis was undertaken with a focus on occupation, the meaning of the inner narrative (Hanninen, 2004; Brockmeier, 2000) communicated a message of occupational persistence. Certain narrative forms dominate particular institutions, such as work institutions (Riessman, 2008) and in the narratives in this study the occupational form of the narrative drew on cognitive schema and the occupational
capital of dominant occupations from past (and in some cases current) engagement. A perseverance of the occupational identity was apparent, which went alongside individuals continuing to engage in similar occupations, employ related discourse in the narrative or frame their current worlds. Past research suggests that continuing to engage in familiar activities helps to re-create inner pictures and subsequently restore occupational engagement (Erikson, Karlsson, Borell & Tham, 2007), so an additional motivation to engage in familiar occupations for those affected by ABI may have been for restoration of identity and connecting to personal values and interests. Striving to maintain an occupational identity after a disruption to the biography is typical (Alsaker & Josephsson, 2013; Nayar & Stanley, 2015).

The sense of occupational history, although compromised (Conneeley, 2012) remained to some extent. Even when those with ABI recounted their narrative and had significant memory issues, (despite recall of narrative requiring drawing on memory), there were still elements of the occupational capital emerging. This finding does not support the claim made by Andrews (2014), that being unable to draw on memory and self-narrate leads to a loss of identity. It would appear that this issue is now less clear and identity issues more complex. Pre-prepared schema held in the mind (Chafe, 1990), part of the individual’s cultural capital, allowed the narrative to reveal these occupational elements.

The narrative identity is a subjective and changing one, continually being revised (Ricoeur, 1991). Potentially unhappiness or despair results when a story of the self cannot be formed (Polkinghorne, 1988). It would appear that as the occupational identity was an identity that participants were very familiar with, it was revealed in the narrative, as new replacement identities may have not emerged and major revisions not yet taken place (Ricoeur, 1991). This illustrates the strength of the occupational identity. Typically in the past rehabilitation services have taken an approach of expecting individuals to come to terms with their new situation and look for alternative occupations linked to their new-found abilities. The findings of this study offer an opportunity to use the established occupational identity as a tool for setting goals, drawing on the embodied occupational capital of the individual, identifying occupations to engage in or frame their view of the future (like the engineering graduate framing his life like an engineering project).

This was apparent for both those with an ABI and significant others. Indeed it is likely that this will not just apply to those whose lives have been affected by ABI, but
it is especially pertinent to this service user group as identity issues and the formulation of a new self-concept is key to adjustment (Klinger, 2005; Hoogerdijk, Runge & Haugboelle, 2011) especially where a return to the previous life situation is not an option (Conneeley, 2012). However, this pre-injury self-concept could perhaps be utilised much more in formulating any new self-concept.

11.3 How engagement in occupations and roles is constructed in the narrative: revelation of embodied occupational identity

How roles had been impacted since the ABI was revealed in the narratives. The worker role had been lost for some, but others had taken up new roles, for example contributing to charities. Many other roles continued but had changed, for example marital relationships, or as a son or daughter. Also the marital role was lost for one, as were sister and daughter roles for another. But in all circumstances it could not be assumed that this was a direct result of the ABI as life carries multiple complexities and pre-injury factors could have contributed. What was evident was that the role of user of healthcare services was only one of many roles and Frank’s (1995) idea that people spend most of their time not being patients was reinforced. Although recruitment to the study had encouraged participation by carers, the carer identity was not one constructed within the narratives and roles of partner, mother etc. foregrounded such identities.

For significant others in the study it was evident that the ABI impacted on roles, with time taken away to devote to caregiving and work and leisure occupations affected too (Martin, 2012). However, an interesting finding was how the occupational identity impacted on roles as well. The cognitive schema and cultural capital was used as a resource in the post-injury situation. Individuals drew on familiar working habits to solve problems in their lives related to ABI. Whether this be utilising techniques from the past role of special educational needs teacher to understand and adapt a partner’s behaviour, or draw on experience as a nurse or human resource manager to contribute to a partner’s rehabilitation. Participants maximised their occupational potential in the post-injury situation (Wicks, 2014). Furthermore, it offers potential for health care professionals working with significant others or carers to adopt an empowered approach and utilise existing cultural capital (including the embodied occupational identity) of significant others in setting goals.
The thesis as a three-act structure is concluded.
References


University Press.


Forslund, M.V., Arango-Lasprilla, J.C., Roe, C., Perrin, P.B., Sigurdardottir, S., &


Phelan, S.M., Griffin, J.M., Hellerstedt, W.L., Sayer, N.A., Jensen, A.C., Burgess,


Appendix A: Information sheet (flyer)

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**Appendix A: Information sheet (flyer)**

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**Who has approved this study?**

The research has been approved by the Research Ethics Committee, School of Social Science and Law, at the University. They have seen into the research in full.

**Who is organising and funding this study?**

The research is part of an MPhil study undertaken by the researcher, funded by Teesside University.

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**Reply Slip**

The challenges and opportunities of participation in crime and communities for people with acquired brain injury and awareness of adults living in rural communities.

If you are interested in taking part please:

- Enter your name and address:
- Enter your contact details:
- Enter your telephone number:
- Please send to:
  - Name:
  - Address:
  - Telephone:

---

**Do I have to take part?**

No. It is up to you. If you do agree you can change your mind at any time until the researcher begins to analyse the data and you don’t have to tell them why. If you are interested, please provide your informed consent during the study.

---

**What will happen if I agree to take part?**

You would be interviewed in your home about your experiences of living with an acquired brain injury or caring for someone with an acquired brain injury, and your experiences of the community you live in. The interview will be arranged for you at a mutually convenient date and time.

---

**What will happen to the information collected about me?**

The information will be kept confidential and the data will be anonymised. As normal with research data, it will be stored securely at Teesside University for 25 years, nothing in the study will identify you, but the data will be stored anonymously. All research results will be reported anonymously.

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**Information Sheet**

This study aims to explore the life stories of adults with acquired brain injury and awareness of adults living in rural communities.

The results will be published and will form part of a 25-year study.

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**How to contact the researcher**

If you have any questions about the research, or if you need to contact the researcher for more information on 01642 381190 (if no reply there is an answer machine) or by email on cyrinda@teesside.ac.uk.

You can ask questions and find out more about the study, including how to take part, to be sure that taking part is right for you.

---

**Do I have to take part?**

No. It is up to you. If you do agree you can change your mind at any time until the researcher begins to analyse the data and you don’t have to tell them why. If you are interested, please provide your informed consent during the study.

---

**People who take part in the research will be asked to:**

1. Be interviewed in their homes about their experiences of living with acquired brain injury or caring for someone with an acquired brain injury, and their experiences of the community they live in.
2. Be interviewed at a mutually convenient time and date.
3. Be interviewed at their home.
4. Be interviewed over a period of time.
5. Be interviewed by the researcher on their own or with another person.
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153. Be interviewed by the researcher on their own or with another person.
154. Be interviewed at a mutually convenient time and date.
155. Be interviewed at their home.
Are you interested in taking part in a research study?

Title: The challenges and opportunities in roles and occupations for adults with acquired brain injury and carers of adults living in rural communities

The research study aims to explore the life stories of adults with acquired brain injury living in rural communities and the life stories of carers or significant others of adults with acquired brain injury, living in rural communities. It forms part of a PhD study.

The results will be published with the intention of promoting a better understanding of the daily issues for people with acquired brain injury and their carers / significant others.

Background to the study

Good health is linked to being able to take part in activities and occupations that are important to us. Some people who have an acquired brain injury may find that being able to take part in such activities is limited and barriers are presented to them. For others it may open up opportunities. The same may be said for carers / significant others of people with an acquired brain injury. Living in different types of communities can make a difference too. The study aims to explore this further.

What will happen if I agree to take part?

You will be interviewed by the researcher in your own home or a nearby convenient location. A second interview will take place a short time later. Before the second interview you will have been left with a digital camera and asked to take some photographs of activities you typically take part in, for discussion in this interview. Your signed consent to taking part will be asked for and information will be treated as confidential. If you change your mind about taking part you will have the opportunity to withdraw and your information will not be used.

What will happen to the information collected?

The interviews will be video recorded and then this data will be analysed. It will be stored securely at Teesside University until the research is complete. All research results will be reported anonymously and identity of those taking part is protected.
What are the disadvantages or benefits of taking part?

It is intended that this study will help to inform others of the situation of people like yourself when considering developments for people with acquired brain injury and carers / significant others. There are no direct benefits to taking part although people taking part in this type of study previously have felt personal benefit from voicing their own story.

Who has approved the study?

The research has approval from the Ethics Committee, School of Social Sciences and Law, Teesside University. The research supervisor is Professor Anna Van Wersch, School of Social Sciences and Law, Teesside University. Tel: 01642 384456 Email: A.Van-Wersch@tees.ac.uk

Who is the research looking to recruit?

- people who have had an acquired brain injury for more than three years
- people who are the carers of or significant others of someone who has had an acquired brain injury for more than three years
- are willing and able to take part in a research interview discussion about their life story
- consider themselves to live in a rural environment

What do I do if I would like to take part?

Contact the researcher, Claire Brewis by mail, phone or email.

Tel: 01642 384130

Email: c.brewis@tees.ac.uk

Address: School of Health & Social Care, Teesside University, Middlesbrough, TS1 3BA.
Appendix C: Instructions for the final interview

The challenges and opportunities of participation in roles and occupations for young adults with acquired brain injury and carers of young adults living in rural communities – Researcher: Claire Brewis

Instructions for the final interview

Thank-you for taking part in the initial interview for this piece of research.

There is one more interview planned. Before the interview takes place I would like you to take some photographs for us to discuss in the final interview. A camera is provided on loan to you to do this, which is simple to operate.

**How many photographs should I take?**
Approximately 10

**What should I take photographs of?**
Typical activities that you do in a day, such as the ordinary main activities that fill your time during the week. This may be something you do in your leisure time, paid work or voluntary / unpaid work. The ordinary things you do are of interest, rather than anything special that you may have planned or go out to do specially for this project.

**Can someone else take the photograph of me doing the activity?**
Yes, if this is what you prefer.

**Who decides what activities to take a picture of?**
You decide. We are interested in what you want to discuss rather than what someone close to you thinks that you should discuss.

**Can I include other people in the photograph?**
No-one else should be included in the photograph unless you have their permission to include them.

**How will the photographs be used?**
We will look at the photographs during the interview and use them as a prompt to discuss how you spend your time and the opportunities or barriers you come across when taking part in activities. Some of the photographs may be used in the final write-up of the research but none will be used if they have a person or recognisable place in the photograph.

**What will happen to the photographs after the interview?**
They will be stored with the research data and archived after the research before being destroyed. If you would like a copy a copy can be supplied on CD for you. They will be wiped from the camera after the interview and the camera is returned.
Appendix D: Comments from a participant on returning their emplotted story to them

Example - P12, Rita

From: [Redacted]  
Sent: 22 June 2015 13:50  
To: Brewis, Claire <C.Brewis@tees.ac.uk>  
Subject: Re: Follow up on the research interviews

Hie Claire,

Have been a bit busy with work. Can you kindly give me a call so we can talk a bit about the research.

My contact number is: [Redacted]

I am off Monday (22.06.15) today and Tuesday (23.06.15) tomorrow. During these two days I will work from home.

You can still phone me on other days, but it’s only to let you know I might be working when you phone.

I will be waiting for your call. In the mean time I will go through your work.

Thank you.

Regards,

■

On 18 June 2015 at 08:47, Brewis, Claire <C.Brewis@tees.ac.uk> wrote:
Hello ■,
Many thanks for getting back in touch with me. I am not at all surprised to hear about your current situation, with this lack of support in coping in the situation you were in when we met.

It would be very much appreciated if you could give some comment as to whether or not you think I captured your story accurately at the time of the interviews. I’ve attached the case study story. There are a number of things to bear in mind on reading it;

- I gave you and ■ pseudonyms to protect identity
- I didn’t precisely mention ■(same reason) or XXXX
- The case study is a snapshot in time and part of the theory behind the research method appreciates that people’s stories change at different times in their lives, so please
don’t worry about your life being in a very different place now in terms accuracy (it was to
capture it at the time of interview)

My supervisors were quite moved about the issues you raised in the story and we had a
discussion about revealing the difficulty you identified specifically about living in [XXX] and
the [XXX] people. I said I’d not been specific to protect identity, but my main supervisor
thought it was something that should be emphasised and published. Can you let me know
what you think about that?

Best wishes,
Claire

Claire Brewis, Principal Lecturer / Subject Leader Occupational Therapy, Teesside
University, Middlesbrough, TS1 3BA | E: c.brewis@tees.ac.uk | 0044 (0) 1642 384130 |
@cbrewistees |

Teesside University is an educational charitable and chartered corporation, exempt under
the terms of the Charities Act 2011
Appendix E:

Table 4 - Length of interviews

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Pseudonym</th>
<th>Gender</th>
<th>ABI or significant other</th>
<th>Length of Int. 1 + 2 (mins.)</th>
<th>Length of Int. 3 (mins.)</th>
<th>Total time (hours + mins.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Rachel</td>
<td>Female</td>
<td>Significant other</td>
<td>129</td>
<td>112</td>
<td>4 + 1</td>
</tr>
<tr>
<td>2</td>
<td>Sam</td>
<td>Male</td>
<td>ABI</td>
<td>124</td>
<td>118</td>
<td>4 + 2</td>
</tr>
<tr>
<td>3</td>
<td>Angie</td>
<td>Female</td>
<td>ABI</td>
<td>126</td>
<td>106</td>
<td>3 + 52</td>
</tr>
<tr>
<td>4</td>
<td>Bruce</td>
<td>Male</td>
<td>ABI</td>
<td>40</td>
<td>56</td>
<td>1 + 36</td>
</tr>
<tr>
<td>5</td>
<td>Susan</td>
<td>Female</td>
<td>ABI</td>
<td>79</td>
<td>49</td>
<td>2 + 8</td>
</tr>
<tr>
<td>6</td>
<td>Hilary</td>
<td>Female</td>
<td>ABI</td>
<td>143</td>
<td>89</td>
<td>3 + 52</td>
</tr>
<tr>
<td>7</td>
<td>Helen</td>
<td>Female</td>
<td>Significant other</td>
<td>110</td>
<td>99</td>
<td>3 + 29</td>
</tr>
<tr>
<td>8</td>
<td>Christopher</td>
<td>Male</td>
<td>ABI</td>
<td>124</td>
<td>148</td>
<td>4 + 32</td>
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<tr>
<td>9</td>
<td>Doug</td>
<td>Male</td>
<td>Significant other</td>
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<td>3 + 35</td>
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<td>10</td>
<td>Elizabeth</td>
<td>Female</td>
<td>Significant other</td>
<td>78</td>
<td>65</td>
<td>2 + 23</td>
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<td>11</td>
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<td>82</td>
<td>2 + 40</td>
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<td>12</td>
<td>Rita</td>
<td>Female</td>
<td>Significant other</td>
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<td>123</td>
<td>4 + 12</td>
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<td></td>
<td></td>
<td>Total data (hours + mins.)</td>
<td></td>
<td>40 + 22</td>
</tr>
</tbody>
</table>
Appendix F: Consent sheet

Unique Identifier no. 

The challenges and opportunities of participation in roles and occupations for adults with acquired brain injury and carers of adults living in rural communities.

Consent form for interviews

Please take the time to read the statements below. If you are happy to take part in the study please initial each box, fill in the bottom of the sheet and return to the researcher.

Name of researcher – Claire Brewis

Please Initial Boxes

1. I have read and understood the information sheet dated and have had the opportunity to ask questions.

2. I am aware that participation in this study is voluntary and I have the right to withdraw up to one month from the interview and do not have to give a reason.

3. I agree that my discussions with the researcher can be video-recorded

4. I have been assured that anonymity and confidentiality will be maintained by the researcher at all times unless any harmful or illegal behaviour is revealed.

5. I understand that the data obtained (interview tapes, transcripts, notes, photographs and paper based documents) will be held securely at the Teesside University and will only be accessible by the research team. Once the final report has been submitted the data will be archived, then destroyed.

6. I agree to take part in this study

----------------------------  --------------------  -------------------
Name      Date    Signature

----------------------------  -------------------  -------------------
Name of Researcher     Date    Signature
Appendix G: Debrief sheet

Unique Identifier no. 

DEBRIEF

Date

The challenges and opportunities of participation in roles and occupations for adults with acquired brain injury and carers of adults living in rural communities.

Researcher: Claire Brewis

Thank you very much for taking part in this study. The aim of this study was to explore the life stories of adults with acquired brain injury and their carers, living in rural communities, to see what barriers and opportunities there are to participating in daily activities.

As previously mentioned in the consent form and information sheets provided, all information and data collected will be kept anonymous and confidential. If you have any further questions about this study I would be more than happy to assist and can be contacted via e-mail on c.brewis@tees.ac.uk or you can contact Professor Anna Van Wersch on A.Van-Wersch@tees.ac.uk. This debrief aims to remind you that you are free to withdraw at any time prior to , without giving a reason and without your rights being compromised. If you would like to withdraw please contact the researcher on the above email address providing your participant number which is in the top right corner of this page.

If you feel that this research may have raised some uncomfortable issues for you and you wish to speak to someone about the issues then support for individuals with an acquired brain or their carers can be found as follows:

Headway – www.headway.org.uk email: helpline@headway.org.uk
Tel: 0808 800 2244

Carers Trust – www.carers.org Tel: 0844 800 4361

Carers UK – www.carersuk.org Tel: 020 7378 4999

Again thank you for your participation
5 December 2012
Claire Brewis

Dear Claire

School Research Ethics Committee

Project title: The challenges and opportunities of participation in roles and occupations for young adults with acquired brain injury and carers of young adults living in rural communities

Researcher(s) Names: Claire Brewis

The above proposal has received ethical clearance and the project may proceed.

If the research should change or extend beyond the indicated dates, the researcher must report the nature of the proposed changes and the revised end date to the Chair/Secretary of the Research Ethics Committee.

Yours sincerely

Dr Martin Tayler
Chair
Research Ethics Committee
School of Social Sciences and Law
# Appendix I: Coding frame for analysis

<table>
<thead>
<tr>
<th>Participant number and pseudonym</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

1. Positional aspects

<table>
<thead>
<tr>
<th>2. Context</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

3. Narrative tone; Optimistic / Objective / Pessimistic

3. Narrative structure; Progressive / Stable / Regressive

Any epiphany moments where goals are redefined?

4. Activities and roles at stages of the life story

<table>
<thead>
<tr>
<th>5. Formation of any identities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Imagery used</td>
</tr>
<tr>
<td>Impression management</td>
</tr>
</tbody>
</table>
6. Values and beliefs e.g.
   a) power / agency (rights and autonomy)
   b) love and relationships (groups and interpersonal relationships)

7. Any shared social stories;
   a) anchoring – concepts given meaning by connecting to the familiar
   b) objectification – concepts acquire meaning through association with everyday phenomena

8. Occupational theoretical concepts

Additional notes:
## Appendix J: Model for photographic analysis

<table>
<thead>
<tr>
<th>Stage 1</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation of data as a whole – (overtones, subtleties, connecting and contrasting patterns)</td>
<td></td>
</tr>
<tr>
<td>Feelings and impressions (and to which particular photos do they belong to?) [<em>Reflexive perspective</em>]</td>
<td></td>
</tr>
<tr>
<td>What questions do the photographs bring to mind?</td>
<td></td>
</tr>
<tr>
<td>How do you respond to any cultural drama i.e. do you have comments about the context of where they were taken and by whom?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stage 2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>[<em>Realist perspective</em>] Log general content</td>
<td></td>
</tr>
<tr>
<td>- activities e.g. self-care / productivity / leisure</td>
<td></td>
</tr>
<tr>
<td>- people included</td>
<td></td>
</tr>
<tr>
<td>- temporal considerations</td>
<td></td>
</tr>
</tbody>
</table>

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>[<em>Contextual perspective</em>] Contextual comments on this content</td>
<td></td>
</tr>
</tbody>
</table>

| Stage 3 – structured analysis |  |
| What does this add to the narrative analysis? (presentation of self in the |  |
What does this add to the analysis of narrative? (themes etc. either within the set of this participant’s photographs or across sets of participant photographs)

Stage 4
Are there any overtones and significance of details? (lay out the set of photographs in entirety to produce conclusions)

Appendix K

Examples of Narrative Analysis Tables – Participant 3, Angie
### Appendix K

**Table 5: Narrative analysis table - Participant 3**

1. **Life story**

<table>
<thead>
<tr>
<th>Identification of phase</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Interview no. / box number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1&lt;br&gt;Growing up – pre-acquired brain injury and hospital experience</td>
<td>Not sure I’ll be able to tell you much about the early days cos I don’t really remember them but Erm, as I say, I can’t really remember, don’t really remember much about me childhood cos sort of my eight, you know I was eighteen it’s sort of been wiped a bit or its very vague. Cos I’d intended after my ‘A’ levels to go to university to do Occupational Therapy. I er, didn’t get very good ‘A’ levels cos erm, my best friend who I did my ‘A’ levels with had leukaemia the same year that I had encephalitis. So I spent quite a lot of my time visiting her and helping her you know getting course work for her and my mind wasn’t really on it. And er I er had my first sort of relationship that year as well so it was just a busy year really and I just wasn’t really focused. I used to be part of a social group when I lived in the Midlands called Rotaract. He was er in special Olympics and had lots of events, you know swimming events, basketball events and competitions and things. So we spent quite a few weekends going to cheer him on and doing that so and my mum worked in a special school so er, you know sort of grew up around lots of people with learning disabilities so that’s what influenced me to go into that sort of line of work.</td>
<td>Consequences of ABI&lt;br&gt;Life stage of biographical disruption&lt;br&gt;Beginning of occupational persistence&lt;br&gt;Typical behaviour of developmental stage / caring for friend and being distracted&lt;br&gt;A social being in youth&lt;br&gt;Occupational persistence&lt;br&gt;Kinship / inheritance.&lt;br&gt;Identifying with disability&lt;br&gt;Occupational persistence and being inspired by the struggle of others&lt;br&gt;A social being</td>
<td>1 / 12&lt;br&gt;1 / 24-28&lt;br&gt;1 / 64&lt;br&gt;1 / 66-74&lt;br&gt;1 / 260&lt;br&gt;2 / 10-22&lt;br&gt;2 / 469-475&lt;br&gt;2 / 1250-1258&lt;br&gt;2 / 1732</td>
</tr>
</tbody>
</table>
Er oh yeah I mean I’ve always had a strong sort of fighting spirit. Cos my brother’s influence, that because you know seeing him through his struggles and stuff with work and other things you know. Sort of inspired me to you know stick at things and give it a good shot so er. My German friend. We, I’d known here since I was 11. We’d been pen friends through school. And then when she turned 17 she er, she got in her car, drove here. I’d been there and done that when I was sixteen and seventeen (partying and drinking)

But Mum’s always been a very practical person and Dad’s quite impatient cos I mean I think growing up with my brother with learning disability, I mean he had quite challenging behaviours and you know quite difficult outbursts. And er, I always found that sort of you know quite scary and you didn’t like the conflict. I’ve never liked conflict because of that I think.

| 2. ABI and hospital | So, when I was just after I’d finished my A’levels. I’d just done my exams, me and my best friend went off to Spain for a holiday and er sort of a girly holiday really. Our first one away on our own. And er, and then when I came back from that, about three days after that I think it was, I got a really bad headache. And that’s when encephalitis struck. And then, they suspected I’d got meningitis. But then I went into a coma. That’s the only thing I remember about being in hospital, having that horrible needle in your back. (laughs) erm, and er and then they finally diagnosed that it was encephalitis.

There was three things they weren’t sure so. And then er, I was in the coma for three days. Woke up on my eighteenth birthday (laughs) and er I don’t remember waking up so

So I was apparently thirsty when I woke up and I said, “Mum can I have a drink.” Well I didn’t say that cos I couldn’t speak so I used my sign language. And Mum said she thought, “Well if she can remember how to use sign language, she must be okay.” | A social being
Experience of being in a family with conflict led to an emotional aversion of it.

A social being
Biographical disruption
Eventual diagnosis
Irony of gaining consciousness on first day of adulthood
Relief at perceived normality
Introduced to poetry as self expression of illness experience
And er, she, she’d wrote poems and stuff about her condition and how it affected her. And that really helped me to understand what she was going through and what was happening to her.

3. Immediately post discharge

So er, I was in hospital for a good month I think it was. After that and then they discharged me and didn’t really tell me anything about you know what might happen afterwards. It was just a case of “You’re well enough to go home now. Bye. Take these tablets for a few months.” I was on steroids I think and then er, that was it really.

And you know I was, I found that difficult cos me and Mum had always been really close. And to hear that from her and sort of “Why? What’s wrong with me?” you know what have it, you know why am I different? And I didn’t really understand.

Yeah. cos I mean although you know Mum and Dad were such a great support and helped me through everything, I didn’t feel that they really understood what was you know what I was going through and how it felt.

And then you feel guilty and then, I mean Mam was really good cos she said, “I know it’s not you and I know, you know And I don’t know, it some, in some way I felt like I was always comparing myself to Mum cos she was quite young when she had us and you know I saw her sort of grow up into a an adult. And er, always sort of wanted to be like her.

Medical model – discharged once physical symptoms gone.

Personal identity / interpersonal relationships affected through striving to be pre-injury self.

Not being understood

Identity of new self v pre-injury self

Kinship / inheritance and a stalled plot

Phase 2

18-24 Completing education and starting work

1. Medical /being diagnosed

And er, after I got home I sort of started experiencing memory problems and didn’t. Had panic attacks er cos I didn’t know where I was or what anything was. Erm, couldn’t recognise erm family members and things. Erm, I wouldn’t remember anything about school-friends and things really. Erm, they’d just, I was okay with mum and dad and my brother, but sort of aunts and uncles and cousins I didn’t know who they were so erm, and then I had a sort of year out recovering really.

Erm, cos after about six months of being at home I was as I say, getting anxiety and panic attacks and had a bit of depression and just wasn’t coping.

Mental health affected by cognitive issues

Unsuccessful striving to be pre-injury self

Mental health issues

1 / 92
really so the doctor referred me to him, and he did some erm, tests on my memory and stuff and said that my visual memory was the thing that was most damaged from the encephalitis. So he referred me to University cos they were doing some research about you know memory problems and things. And they did all sorts of tests on me and er, diagnosed that I had prosopagnosia. But then when, after I was poorly and she'd gone I didn't really have any friends. Cos none of them really understood why I couldn’t remember who they were or couldn’t have. Cos conversations were very difficult. when I, used, when I was first poorly erm, Mum contacted the ME support group cos the doctor diagnosed me with ME. Erm, my short term, memory was very bad at that point, so you know I couldn’t remember what I’d done that morning. And er, sort of sequencing things was difficult as well. You know, I had to write instructions, write physical instructions how to use it. Erm, and my visual memory was very poor, so I couldn’t recognise places as well as faces. Erm, and I’d get lost or disorientated. I wouldn’t know where I was. My appetite was affected initially. I hadn’t really got much of an appetite and er. My taste was affected too. So er, I got very frustrated with you know not sort of knowing who anybody was, not being able to er, sort of have much of a social life at that point. I wasn’t sleeping. Er, I used to get really vivid nightmares as well. I think that’s another reason why I struggled with making friends, cos they got fed up with all of that. Couldn’t be bothered to you know hang around while I did all that. (plan) And it was all, you know with the fatigue and things it was too much to stay out late at night and do that so

| Specific diagnosis of cognitive issues | 1 / 232-234 |
| Social isolation | 1 / 238-240 |
| Social awkwardness | 1 / 290-292 |
| Fatigue | 2 / 30-32 |
| Cognitive issues | 2 / 36 |
| Executive functioning issues | 2 / 48 |
| Poor visual memory | 2 / 68-70 |
| Sense of taste affected | 2 / 110-112 |
| Social isolation | 2 / 148-150 |
| Emotional impact | 2 / 178-180 |
| Social identity | 2 / 1222-1226 |
| Fatigue | 3 / 958-960 |
2. Identity

I’d been, “Well who am I?” and you know very sort of anxious about what had happened, and what people thought of me and very nervous about being around new people and stuff and just constantly questioning, “Who am I?” really.

I had quite a tough time with Mum and Dad. Where apparently I was, I mean I can remember getting very cross and frustrated with them easily and my moods were up and down like a yoyo er and er, it was weird really cos you don’t really know. It’s like you’re sort of sitting and watching yourself, be totally different, and a way you wouldn’t be. And there’s nothing you can do about it. And you feel really guilty afterwards and think, “Why did I do that?” (laughs)

Erm, the thing that I remember getting very anxious about was whether I’d locked the door.

Always putting myself down and stuff whereas now When I was sort of in my sort of really down period after my friend had died and everybody had gone away and stuff, erm she suggested I read this book that she’d read called “feel the fear and do it anyway” by Susan Jeffers. And again, that was a, a turning point for me cos there was lots of things in there that just made complete sense.

| 2. Identity | Personal identity and social identity | 1 / 323-327 |
|  | Behavioural issues due to frustration impacting on family dynamics | 1 / 337-339 |
|  | Feeling guilty at lack of self control | 2 / 60 |
|  | Anxiety | 2 / 2727 |
|  | Negative chatter | 2 / 2731-2735 |

3. Education

So I didn’t get the grades I wanted so I decided to try and go back to college and do another course, but I was a bit worried about how I was gonna manage that cos I couldn’t remember things and thinking, “How am I gonna do exams?” so I did a B-Tech which was more sort of coursework related.

And er, that was hard work.

I went to University to do an Occupational Therapy course

It was okay academically. But the, when I went on the occupational therapy placement, I had difficulties with erm, my sort of recognition really.

So they failed me on the placement side. They said the academic side I was fine, I’d passed everything. It was just purely the professional bit

So er I had to, it was quite sort of heartbreaking time at that time cos it was

| 3. Education | Stalled plot not due to ABI | 1 / 74 |
|  | Occupational persistence of helping people | 1 / 82 |
|  | Visual memory issues | 1 / 102-104 |
|  | Zone of proximal engagement – required more strategies | 1 / 136 |
|  | Biographical disruption | 1 / 142 |
|  | | 1 / 146 |
|  | | 2 / 411- |
you know something I'd always wanted to do. And they, I transferred to the Health Sciences course. You know that they were telling me without writing them down and things. And it just sort of you know, er I didn't feel like they were you know, going to let me through it and and I, I couldn't really do anything else other than what I was doing. So er, I had to sort of give in in a way. I mean he'd actually told me he didn't think I was gonna be capable of getting a degree anyway, and er, he, cos he'd said when I first applied, he thought I would struggle.

And the rest of us went into sort of voluntary sector type jobs cos that was all we could get in to. I mean I've found particularly you know with university thing, when I made a big issue of it and sort of said, "This is you know my problems and this is how I need you to you know support me." That it didn't work.

And when I was at erm, at university and struggling with you know getting to know people and stuff I got a poem that came into my head and that helped me say you know how, you know it got out some of my frustrations Walking round the town centre and I remember a guy smiling at me. Because he'd smiled at me, I thought he knew me.

| 4. Moving to a rural area | So er, and then we moved up here in my final year when I finished Uni cos mam and dad had al, we'd always come up to [missing] as erm, sort of family holidays since I was about three. You know so it’s like a second home really. | Stage of not having had chance to firm up coping strategies | 417 2 / 433
| 5. Looking for first post | I was looking for jobs and things erm, as the dissertation I did for Uni was around people with learning disabilities and supported employment and whether they needed advocacy to help them speak. Cos my brother had been through erm, supported employment. And he had all sorts of problems where they'd discriminated against him. When we’d had to speak up for him and I just thought, “There’s nobody there doing that” so wanted to looking into it a bit more. | Medical model – low expectations of a disabled person | 2 / 840-842
|  |  | Revealing / not revealing invisible disability due to discrimination / social identity issues | 2 / 1170-1176
|  |  | Coping through poetry | 2 / 1888-1894
|  |  | Personal safety issues due to visual memory | 2 / 2621-2623
|  |  | Occupational persistence | 1 / 152-154
|  |  | Family co-operation / social capital | 1 / 154-158
|  |  |  | 1 / 162
I applied, I didn’t get it when I first came up cos they said I hadn’t got enough experience. Er yeah, I had trouble I was about six, unemployed for about six months. Er so I went onto a New Deal scheme with the JobCentre where they put you on a placement somewhere. So I and er, I asked to change and go onto something a bit more people centred cos I knew I wanted to work with people more. Er I worked there with them for three years part time. And er, but funding was always an issue cos it was a voluntary organisation.

6. Career development

Oh yeah I went to a housing association as a housing support worker. And it didn’t really stretch me very far. So I was looking for something else. And then I got the job at erm Social Services as a community care officer. And er, that was a challenge (laughs) I didn’t have, I mean didn’t have a particularly good relationship with my er, my manager. I did for the first couple of years, but she became a bit of a bully and er, it got to the stage where I felt the role was becoming unsafe. Cos I was going to bed worrying about what I’d gotta do the next day and then waking up at three in the morning and then being tired and and that makes my memory worse so I was forgetting things and I just, it just sort of got to the point where I just thought, “I can’t do this.”

7. Travelling abroad

I took six months out cos I’d always planned when I was at school to go and work abroad and do some travel. And she’d been travelling and working out there for a year. So I went out and did a six-week holiday with her. And she was sort of you know showing me how she you know got places and travelled round. As I say, spent the first few weeks with and getting familiar with everywhere and then er, did a bit of travelling round er. Yeah, erm, I mean the, I worked in one, one particular home I did a few shifts in and there was a day centre I did a few in. So that was er, I mean it was good in one way because you were meeting
new people on a daily basis so they didn’t know I hadn’t got a clue who anybody was.

**Phase 3**

**Mid-twenties to current day**

**1. Work**

When I first, you know work was my main focus and particularly with the social services job, I felt like it got to a point where it was just all work and no play and that’s why I wanted a change really. Cos I didn’t think it was doing me any good. I thought I was gonna become poorly. So, and er, I had a look round.

And I’m a care and support manager. Erm, and er, I’m responsible for several houses in the village
And er, I did go through a difficult phase where I wasn’t managing things and I was forgetting things and people were noticing you know that I wasn’t keeping up.

Yeah. I mean I guess, I'm I'm sort of lucky in the way that my work you know has fallen in that I can do more, you know very similar to what I was hoping to do anyway.

**2. Charity involvement**

And it was them that then told me about the encephalitis society.

I think er, that was about 2002 I think it was. It was the first retreat they’d ever done.

And, and that was the first time since having the illness that I actually thought, “Ah, that’s what it’s all about.” (laughs) So I’m not, not abnormal. Other people have got it.

Now I volunteer for them.

they were also doing a fundraising project erm, sort of trek in Transylvania And I’d signed up to help with that. And we, we were at the annual general meeting and they said, “Hands up who’s going on the trek.” And we, we both put our hands up. So I went and had a chat with her afterwards. And she said, “Oh hi I’m [name].” And I said, “How’s it affected you?” and she said, “Oh I’ve got prosopagnosia.” And I said, “No” (laughs) “So have I.” (laughs)
I’d looked at it and thought, “Oh no I don’t really wanna go and meet all those new people.” Cos I was a bit nervous about it and stuff, but I showed it to Mum and er, and said, “What do you think?” she said, “I think you should go for it.”

As I say it was a big relief. (laughs) Erm, yeah, yeah, I mean it was, it’s an hilarious weekend cos you know lots of people with remembering problems (laughs) hadn’t got a clue who anybody was so we spent the whole weekend going, “Who are you again?”

And it sort of, he seemed to get to a sort of turning point and it was really nice to be part of that

And as I said, the er, the retreat made me write a poem

And I’ve sent a couple of others into the newsletter.

Erm, well to be honest, I’m struggling with it at the moment cos work’s so busy. And I don’t really feel I’ve you know, got the energy or time.

3. Revealing disability

It’s difficult though with you know, how much to tell people when you meet them and stuff. Cos you don’t want them to feel sorry for you and treat you any differently. But you also don’t want them to think, “Oh why’d she not remembering this?”

And I’m a bit, I don’t know, I guess I’m a bit anxious now. About sort of making a big issue of it. Cos when people focus on it I think it makes it worse. Whereas if they just let me get on with it and find my own strategies without, you know pressurising me.

4. Social situations

But with you know, work situations and social situations I didn’t find it as easy cos you know you’re not, don’t always see people every week. And er, it’s hard to sort of use those strategies without feeling totally stupid. (laughs). And I am worried you know, conscious about it

It was nice Yeah. Someone to go to the cinema with. Bowling or do things. So cos you know hadn’t really been going out.

It was about two years ago, I found a group called Spice which is a sort of
social group for adults and the group sort of folded unfortunately
I can’t be very spontaneous sometimes cos you have to plan things so
meticulously to be able to remember everything.
And er, yeah and then I didn’t sort of do, didn’t do you know just did the bits
with Mum and Dad really sort going to the pub quiz cos they go to the pub
quiz once a week and er, and went out with my brother and that was sort of
you know
Yeah. so that’s been a challenge to meet anybody my age really. And I
don’t know whether, I mean I’m not a big drinker because I can’t taste.
I’d been there and done that when I was sixteen and seventeen. You know I
didn’t really want to keep doing that.
But I still, I mean we, we are close but but we’re not like we were before.

One thing I still struggle with is knowing who lives where and who me
neighbours are
So you know when we have events in the village hall and stuff, it’s like going
into a room with strangers but

I’ve been going out with him for two years now.
And he was in the same rehab unit as (friend) and that’s how they got to
know each other
I mean most of my friends are up to an hour’s drive away.
I mean I’d tried to join the badminton group here in (local town) when I
first moved up here, but they were very insular and hard to get to know.

Restricted access to
usual social groups due to;
A – cognitive issues
B – social identity issues
C – having different interests to others of similar life stage
Family dynamics
Cognitive issues
Social isolation

2 / 1206-1208
2 / 1590-1594
2 / 1710-1714
2 / 1732-1736
2 / 1850-1852
2 / 2357-2359
2 / 2373
23 / 161
3 / 179-181
3 / 589
1 / 280
5. Coping

Er, and if I wanted to go anywhere, I’d have to get Mum and Dad to sit down and do, you know instructions with how to get there and then, go on, depending how complex the route was, go on a practice run with them. Until I eventually got a sat nav which is the best invention ever (laughs) I’m still not great with walking about. Get disorientated, you know when I come out of a building I don’t know whether I’ve gotta go right or left. Tomorrow I couldn’t necessarily remember what I’ve done today

Yeah, cos I don’t know you, you’re always worried you’re gonna make the wrong decision or, you know, do something wrong
Sometimes, you know mum and dad’ll talk about something and I’ll remember the tiniest little thing
Yeah. cos I do, I do use them to sort of retrieve memories and stuff.

I think it’s probably made me, I don’t know, stronger and a bit more open to things and than I might have been then.

| Orientation in place issues | 2 / 575-581 |
| Memory                     | 2 / 595-597 |
| Decision making issues     | 2 / 609-613 |
| Chinks of remembering     | 2 / 671-673 |
| Positive impact of ABI     | 3 / 739     |

2 / 2787-2789
3 / 888
3 / 2813-2817
Table 6: Narrative analysis table – Participant 3

<table>
<thead>
<tr>
<th>Event</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Interview number / box number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Being taken ill</strong></td>
<td>Sort of my eight, you know I was eighteen it’s sort of been wiped a bit. So, when I was just after I’d finished my A’levels.  I’d just done my exams, me and my best friend went off to Spain for a holiday and er sort of a girly holiday really. Our first one away on our own. And er, and then when I came back from that, about three days after that I think it was, I got a really bad headache. And that’s when encephalitis struck well my dad asked what they thought it was and they said they didn’t really know what was wrong with me. And Mum said she thought, “Well if she can remember how to use sign language, she must be okay.” (laughs) So er, I was in hospital for a good month I think it was. After that and then they discharged me and didn’t really tell me anything about you know what might happen afterwards. It was just a case of “You’re well enough to go home now. Bye. Take these tablets for a few months.” I was on steroids I think.</td>
<td>Social representation of biographical disruption</td>
<td>1 / 26 1 / 36</td>
</tr>
<tr>
<td><strong>Post hospital discharge</strong></td>
<td>Erm, I wouldn’t remember anything about school-friends and things really.  Erm, they’d just, I was okay with mum and dad and my brother, but sort of aunts and uncles and cousins I didn’t know who they were so erm, and then I had a sort of year out recovering really. Cos I’d intended after my A’levels to go to university to do Occupational</td>
<td>Cognitive issues Occupational persistence Activities during life</td>
<td>1 / 60-62 1 / 64 1 / 66-70</td>
</tr>
</tbody>
</table>
Therapy
I er, didn’t get very good ‘A’ levels cos erm, my best friend who I did my
‘A’ levels with had leukaemia the same year that I had encephalitis. So I
spent quite a lot of my time visiting her and helping her you know
getting course work and things for her and my mind wasn’t really on it.
Cos I, I found that a er, my erm, thought process was much slower and
it took me longer to sort of I don’t know, work things out and structure
things. So writing essays took me a long time and I needed extra time
for stuff.
Erm, cos after about six months of being at home I was as I say, getting
anxiety and panic attacks and had a bit of depression and Just wasn’t
coping really so the doctor referred me to him, and he did some erm,
tests on my memory and stuff and said that my visual memory was the
thing that was most damaged from the encephalitis. And I was having
particular problems with recognising people and knowing who people
were.
But then when, after I was poorly and she’d gone I didn’t really have
any friends
You try and make notes and stuff but it’s very false if you sort of trying
to build up a relationship and you’re scribbling notes about some people
all the time.
Mum contacted the ME support group cos the doctor diagnosed me
with ME
up until that point I’d been, “Well who am I?” and you know very sort of
anxious about what had happened, and what people thought of me and
very nervous about being around new people and stuff and just
constantly questioning, “Who am I?” really.
Er and er, it was weird really cos you don’t really know. It’s like you’re
sort of sitting and watching yourself, be totally different, and a way you
wouldn’t be. And there’s nothing you can do about it. And you feel

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<tr>
<th>stage of adolescence</th>
<th>1 / 76-80</th>
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<tbody>
<tr>
<td>Time required to firm up</td>
<td>1 / 88-92</td>
</tr>
<tr>
<td>coping strategies</td>
<td>1 / 232-234</td>
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<tr>
<td>Mental health issues through</td>
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<tr>
<td>striving to be pre-injury self</td>
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<tr>
<td>Social isolation</td>
<td>1 / 244</td>
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<tr>
<td>Inappropriateness of</td>
<td>1 / 290-292</td>
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<tr>
<td>applying coping strategies</td>
<td>1 / 323-327</td>
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<tr>
<td>Fatigue</td>
<td>1 / 339</td>
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<tr>
<td>Identity / social</td>
<td>2 / 42-46</td>
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<tr>
<td>awkwardness</td>
<td>2 / 76-78</td>
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<tr>
<td>Identity / guilt at lack of</td>
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<td>self control and</td>
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<tr>
<td>awareness of right and</td>
<td>2 / 148-150</td>
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<tr>
<td>wrong</td>
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<tr>
<td>Executive functioning issues</td>
<td></td>
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<tr>
<td>Sense of taste affected</td>
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</table>
really guilty afterwards and think, “Why did I do that?” (laughs)
Erm, using equipment and things at home was difficult. So I had real
trouble with the washing machine. I just got a block.
And I, I’d ring Dad and say, “Help. I don’t know where I am.” (laughs)
Which was rather scary.
Things tasted stronger and erm, certain foods I can’t, er couldn’t eat. I
still can’t now.
So er, I got very frustrated with you know not sort of knowing who
anybody was, not being able to er, sort of have much of a social life at
that point.

Social isolation

And they were quite supportive initially. And said they should be able to
adapt things. Erm, so I started the course and did the first year. It was
okay academically. But the, when I went on the occupational therapy
placement, I had difficulties with erm, my sort of recognition really. It
was the I had an issue on one placement,
And it was erm, was meant to help clients a lot and I was you know,
having to write notes and things during the sessions. And they said that
was unprofessional.
He looked very similar and they said that that was unsafe practice.
So er I had to, it was quite sort of heartbreaking time at that time cos it
was you know something I’d always wanted to do.
And er, managed to er successfully get through that one thankfully.
I have the strategies but they wouldn’t sort of let me use them. So it put
me at a disadvantage in a way.
But it, I don’t know, it had taken me so much effort to even get to
university in the first place and then to get on the course that I’d always
wanted to and, I don’t know I don’t think I was strong enough to fight
them at that point.
I mean he’d actually told me he didn’t think I was gonna be capable of
getting a degree anyway, and er, he, cos he’d said when I first applied,
| Mistaking a stranger for a friend | I remember at Uni, not knowing who people were was a bit risky in a sense. You know cos walking round [redacted] cos I went to Uni at [redacted]. Walking round the town centre and I remember a guy smiling at me. Because he'd smiled at me, I thought he knew me. And er, and then he said, “oh do you want to come, come with me,” or something. And I thought, “Oo God. Who’s this? What?” Cos I didn’t know who he was, I said, “Do I know you?” and he said, “No but” (laughs) I thought, “Oh my God I could have got myself into real you know, mess there.” | Personal safety issues due to poor visual memory | 2/2617-1633 |
| Travelling in Australia and New Zealand | I took six months out cos I’d always planned when I was at school to go and work abroad and do some travel but I never actually managed it cos the illness and stuff. And she’s always done travelling and stuff and inspired me, you know cos she was always here there and everywhere. And er I mean it was handy cos a lot of the hostels when you travel somewhere new, they pick you up from the station so you get sort of door to door service. Wouldn’t have to find your way which was helpful. Er, but then I, when I was in Australia I was, er managed to get this job with the agency. In New Zealand was a bit more of a sort of social thing. So that was er, I mean it was good in one way because you were meeting new people on a daily basis. So they didn’t know I hadn’t got a clue who anybody was. So that was sort a bit of a relief cos nobody knew anybody so I could just pretend and flow along with everybody else. And I can remember thinking, “How am I going to recognise my pants and stuff?” You know and I felt really awful cos I thought, well they’d made a real effort and invited me to go along and they’re gonna think I’m really rude. | Achieving goals / ambition | 1/214-216 |

Looking to others for inspiration  
Impact of the environment / social situation and being able to appear normal  
Occupational persistence  
Impact of the social situation and being able to appear normal  
Social boundary of being polite crossed due to cognitive deficits | 1/222  
2/1313-1317  
2/1329  
2/1412  
2/1422-1430  
2/1446  
2/1491  
2/2657-2659 |
And then at breakfast I went down and sort of you know started saying, “Oh where are you from? Are you travelling round?” as if I didn’t know her.

<table>
<thead>
<tr>
<th>Introducing self to charity</th>
<th>Social isolation</th>
<th>2 / 1762-1770</th>
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<tbody>
<tr>
<td>So that’s, that’s when I went round and you know said, cos I think I, yeah I was going through a bad patch about sort of feeling lonely and not having any, and I’d written to the society erm, I think they’d got, they’d got some sort of matching scheme or something where they match you with other people with similar problems. And then I went down, cos they were having an open day and er, the lady who I’d sent the letter to recog you know said, “Oh are you the [redacted] that sent me?” you know and I said, “Yes” and then that was sort of starting point really. I’d looked at it and thought, “Oh no I don’t really wanna go and meet all those new people.” Cos I was a bit nervous about it. And stuff, but I showed it to Mum and er, and said, “What do you think?” she said, “I think you should go for it.” Yeah. It was her sort of support and enthusiasm about it that made me do it. I’m glad they did now cos as I say it was a big relief. (laughs)</td>
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<tr>
<td>Beginning of a new life chapter</td>
<td>2 / 1776-1782</td>
<td></td>
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<tr>
<td>Social anxieties overcome</td>
<td>2 / 1790-1800</td>
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<thead>
<tr>
<th>Charity retreat</th>
<th>Interpellation “that’s me”</th>
<th>1 / 321-323</th>
</tr>
</thead>
<tbody>
<tr>
<td>And that was the first time I’d ever met anybody else who’d had encephalitis. So all got the same problems and it was, it was really nice cos up until that point I’d been, “Well who am I?” and you know very sort of anxious about And, and that was the first time since having the illness that I actually thought, “Ah, that’s what it’s all about.” (laughs) So I’m not, not abnormal. Other people have got it. I think that was a turning point really in life for me. Cos up until that point I’d I don’t know, I don’t know that I’d really accepted what had happened. Erm, yeah, yeah, I mean it was, it’s an hilarious weekend cos you know lots of people with remembering problems (laughs) hadn’t got a clue</td>
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<tr>
<td>New life chapter – acceptance</td>
<td>1 / 329-333</td>
<td></td>
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<tr>
<td>Connecting with others. Identity issues</td>
<td>1 / 337</td>
<td></td>
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<td></td>
<td>2 / 1802-1808</td>
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</table>
who anybody was so we spent the whole weekend going, “Who are you again?” (laughs) “And what was your name?” but it was nice cos you could laugh about it. You know cos ever, up until that point I’d been, you know, nervous about saying to people that I couldn’t remember their name or felt stupid about it.

You know cos ever, up until that point I’d been, you know, nervous about saying to people that I couldn’t remember their name or felt stupid about it.

I remember there was a guy who er, he’d had a quite a difficult time and he opened up in the group and said a few things and it sort of, he seemed to get to a sort of turning point and it was really nice to be part of that and er, I can’t remember what it, what he was talking about now but er, and I don’t know, it was just a really nice comfortable, we all got on.

And that was the first sort of social situation where I felt normal. And you know I was, I found that difficult cos me and Mum had always been really close. And to hear that from her and sort of “Why? What’s wrong with me?” you know what have it, you know why am I different? And I didn’t really understand.

cos I mean although you know Mum and Dad were such a great support and helped me through everything, I didn’t feel that they really understood what was you know what I was going through and how it felt. Whereas the people at the retreat knew exactly how it felt and could say “Oh yeah well I do this” and Cos there was erm, who, she, she had a different type of encephalitis to me er, which left her in a wheelchair. She now needs carers to do most things for her and she you know, she was married with two kids and you know so she was, I don’t know. I just thought, “Gosh you’ve been you know. She’s a lot worse off than me you know.

| Social acceptance / identity | 2 / 1808 |
| Catharsis / connection | 2 / 1814-1818 |
| Social identity | 2 / 1822 |
| Inspired by others who had struggled | 2 / 1834-1840 |
| Comparison processes | 2 / 1860-1866 |
| 2 / 2134-2150 |
I've just memory problems and taste problems. You know at least I can walk and you know I don't have to have people do things for me so it made me feel, you know put it into perspective really.

| Transylvania trek | And I'd signed up to help with that. And we, we were at the annual general meeting and they said, “Hands up who’s going on the trek.” And we, we both put our hands up. So I went and had a chat with her afterwards. And she said, “Oh hi I’m [XXX].” And I said, “How’s it affected you?” and she said, “Oh I’ve got prosopagnosia.” And I said, “No” (laughs) “So have I.” (laughs) Cos people’ll say, “Oh yeah. I have problems with my memory.” Or “Oh yeah, I forget who people are.” But it’s not the same.
 | That was a challenge. (laughs) And er, (laughs) me and [XXXX] (friend) were sat round the table on the second night and we were both sort of (laughs) dropping off. [XXX] said, “You two need to go to bed.” Cos we just weren’t just couldn’t think or wurr. Oh but it was good. Good. The chap said that we were the only group that had done that day without needing a bus to come and rescue somebody. Erm, it was nice sort of socially you know. And it was raising money and saying thank you to the society for the you know the help they’ve given me. Erm, and er, dunno. It was just a challenge really. I like challenges. Need to with this condition. |

| Working at SSD | As I say at the end when I left it I’d got 103 people I was responsible for so And er my little index box became quite quite useful cos people kept pinching it (laughs). Yeah. erm, I mean it, my, as I say my boss was er quite a challenge (laughs). She put quite a lot of pressure on and er, didn’t really, I don’t know that she fully understood the difficulties I had. She er, criticised me when I didn’t manage sometimes and er you know |

| Identifying with others | 1 / 365 |
| Overcoming challenges | 1 / 369 |
| Helping the charity / social acceptance | 2 / 1969 |
| Coping strategies helpful to all | 2 / 2006-2018 |
| Stress of work | 2 / 2036-2044 |

| Coping strategies helpful to all | 1 / 985 |
| Stress of work | 2 / 1027- |
I found that quite difficult. Erm, but er, but then you know as I got more into the job she expected more of me and and you know seemed to forget those early days and what I needed. So erm and er it got to the point as I say that I was you know, living and breathing work all the time. Cos I was going to bed worrying about what I'd gotta do the next day and then waking up at three in the morning and then being tired and and that makes my memory worse
### Table 7: Narrative analysis table – Participant 3

#### 3. Illness experience

<table>
<thead>
<tr>
<th>Issue</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Interview / box number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Being diagnosed</strong></td>
<td>And then, they suspected I’d got meningitis. But then I went into a coma. And er, they said to my dad well my dad asked what they thought it was and they said they didn’t really know what was wrong with me. And er they were gonna transfer me to the neuro hospital. So they did that and then they did lumbar punctures and all sorts of things. That’s the only thing I remember about being in hospital, having that horrible needle in your back. (laughs) erm, and er and then they finally diagnosed that it was encephalitis. And started treating me with acyclovir cos they were treating me for a brain tumour and two other things in the local hospital. That was a er, don’t know. Yeah it was meningitis, a brain tumour and something else.</td>
<td>Anxieties for family before diagnosis when seriously medically unwell</td>
<td>1 / 38-42</td>
</tr>
<tr>
<td><strong>Hospital discharge</strong></td>
<td>After that and then they discharged me and didn’t really tell me anything about you know what might happen afterwards. It was just a case of “You’re well enough to go home now. Bye. Take these tablets for a few months.” I was on steroids I think. And then er, that was it really. Cos I, I found that a er, my erm, thought process was much slower and it took me longer to sort of I don’t know, work things out and structure things. So writing essays took me a long time and erm, but I got through it eventually. (laughs) and er, got the grades I needed to get into Uni Erm, cos after about six months of being at home I was as I say, getting anxiety and panic attacks and had a bit of depression and just wasn’t coping really so the doctor referred me to him, and he did some erm, tests on my</td>
<td>Medical model. Discharged once physically better Cognitive issues Medical model. Discharged once physically better Cognitive issues Medical model. Discharged once physically better Cognitive issues Medical model. Discharged once physically better Cognitive issues</td>
<td>1 / 54-58 1 / 76-82 1 / 88-92</td>
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memory and stuff and said that my visual memory was the thing that was most
damaged from the encephalitis. And I was having particular problems with
recognising people and knowing who people were. So he referred me to University cos they were doing some research about you know memory
problems and things. And they did all sorts of tests on me and er, diagnosed
that I had prosopagnosia
Erm, my short term memory was very bad at that point, so you know I couldn’t
remember what I’d done that morning
And er, sort of sequencing things was difficult as well.
And er, I couldn’t, I had to get a sort of tablet case thing to help remember
whether I’d had them or not cos you know I couldn’t remember and I was
worried about taking too many.
Erm, and my visual memory was very poor, so I couldn’t recognise places as
well as faces Erm, and I’d get lost or disorientated. I wouldn’t know where I
was.
My appetite was affected initially. I hadn’t really got much of an appetite and
er my taste was affected too.
Er cos of the, some of the research that that lady did at the university, she said
my verbal memory was better than my visual memory.
So er, I got very frustrated with you know not sort of knowing who anybody
was.
I wasn’t sleeping. Er, I used to get really vivid nightmares as well.
You know and er, they erm, after they’d diagnosed the prosopagnosia, she
was doing a project around strategies and stuff for managing that.
Don’t, I don’t know, guess it’s the fear of you know, bumping into an old
school-friend and not having a clue who they were or

<table>
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<tr>
<th>At University</th>
<th>proximal engagement</th>
<th>2 / 36</th>
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<tr>
<td>And failed me on the placement, but er, oh and the other reason was because I was doing home visits and things, I was having to draw myself a picture of you know what the house looked like and stuff cos I couldn’t visually remember it. And again they said that was unprofessional and unsafe practice, so they</td>
<td>Executive functioning issues</td>
<td>2 / 54-58</td>
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<td>2 / 68-70</td>
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<td>2 / 178-180</td>
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<td></td>
<td>Emotional psychological impact</td>
<td>2 / 228</td>
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<tr>
<td></td>
<td>Social awkwardness</td>
<td>3 / 695</td>
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<tr>
<td></td>
<td>Irony of vocational programme – not being allowed more time to firm up coping strategies</td>
<td>1 / 130-134</td>
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<td>1 / 142</td>
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wouldn’t let me use, you know the strategies I needed to do the job. So er I had to, it was quite sort of heartbreaking time at that time cos it was you know something I’d always wanted to do. But I think you know they were, I felt that they gave up on me too easily. It was just a big disappointment and you know really. The end of the world really.

Future life script destroyed

Socialising

But sort of finding social outlets with people my own age was difficult. And er, there was only sort of one or two close friends that stayed in touch. Cos none of them really understood why I couldn’t remember who they were or couldn’t have. Cos conversations were very difficult. Still is really cos you, you know people tell you things and you want to be able to remember them. You know, when you’re sort of first getting to know somebody and trying to build a relationship you’re sat there scribbling things about them it’s not very nice. think that’s another reason why I struggled with making friends, cos they got fed up with all of that. Couldn’t be bothered to you know hang around while I did all that. But most of them are older than me. They’re sort of like forties, early fifties. Yeah. so that’s been a challenge to meet anybody my age really. And I don’t know whether, I mean I’m not a big drinker. And er, I don’t know, I found that people my own age just like to go out and get drunk. And you know, it just wasn’t sort of anything I was interested in doing really.

Social isolation
Social awkwardness – social identity / representations
Stigma
Absence of friends at same developmental stage

Charity involvement
Er, what else to tell you (laughs) erm, oh erm, when I, used, when I was first poorly erm, Mum contacted the ME support group cos the doctor diagnosed me with ME. Erm, in that first year after the illness cos I was very lethargic and I hadn’t got any energy. So I er went, went over and said “Hello” to them and found out something.

Fatigue
Interpellation
And that was er, the first person I spoke to who knew what prosopagnosia was. So all got the same problems and it was, it was really nice cos up until that point I’d been, “Well who am I?” and you know very sort of anxious about what had happened, and what people thought of me and very nervous about being around new people and stuff and just constantly questioning, “Who am I?” really.

So, but that sort of, that weekend helped me to understand you know some of that so, I’ve been involved with them for, ever since really and made some good friends through it.

But I think er, you know that the society’s helped me cope with that cos I know, I know there’s other people and you know we all have different ways and we can help each other with you know, suggesting different things. So, makes it easier now so, whereas before, I used to get really frustrated with myself and cross and angry so, always putting myself down and stuff whereas now She was the sort of you know the person that helped me to laugh about the problems

I think that was a turning point really in life for me. Cos up until that point I’d I don’t know, I don’t know that I’d really accepted what had happened. I don’t know you sort, it’s difficult cos me Mum and Dad you know said I wasn’t the same as I used to be. And you know I was, I found that difficult cos me and Mum had always been really close. And to hear that from her and sort of “Why? What’s wrong with me?” you know what have it. You know why am I different? And I didn’t really understand Yeah. And I don’t know, it some, in some way I felt like I was always comparing myself to Mum cos she was quite young when she had us. And you know I saw her sort of grow up into a an adult. And er, always sort of wanted to be like her. And then with you know with the problems I was having you know I felt like I was constantly comparing myself and thinking “Oh, I’m not good enough.”
Mood

And er, oh I’ve missed a bit really cos I had quite a tough time with Mum and Dad. Where apparently I was, I mean I can remember getting very cross and frustrated with them easily and my moods were up and down like a yoyo. Er and er, it was weird really cos you don’t really know. It’s like you’re sort of sitting and watching yourself, be totally different, and a way you wouldn’t be. And there’s nothing you can do about it. And you feel really guilty afterwards and think, “Why did I do that?” (laughs)

Yeah. Yeah. cos I mean I think growing up with my brother with learning disability, I mean he had quite challenging behaviours and you know quite difficult outbursts. And er, I always found that sort of you know quite scary and you didn’t like the conflict. I’ve never liked conflict because of that I think. And to think I was doing that to Mum and Dad, just made me feel awful. Cos it wasn’t me. I was never like that so

Strategies for coping

And er we er, developed a strategy for recognising each other the next time we met. Cos the symbol of the society is a jigsaw piece and it’s sort of red and blue. So she cut out a red jigsaw piece for her, and I’ve got a blue piece. So whenever we meet up we hold up the jigsaw pieces, so we know it’s each other. Mine’s on the board up there (laughs) And we also made last ti... was it last year, I think it was last year, we made some necklaces that were very similar.

But her I had very a supportive year tutor. So she helped me through thankfully. She understood quite well.

And the third one was I’d got to try and link something about what they look like, to their name or something.

Erm, when I was at er, college, I found it difficult to sort of with, you know when you’re reading books and stuff and you needed to sort of go back to things, I could never remember where they were, so I used post it cards.

Er, diary’s essential (laughs)

So I used to print road by road instructions off that way until I eventually got a sat nav which is the best invention ever (laughs) cos I can find my way round
without worrying about it now. And I think she inspired me in terms of work as well cos you know she struggled with things and you know was stubborn like me (laughs) and you know persevered and got round things. And I thought, "Well if she can do it, I can do it."

And when I was at erm, at university and struggling with you know getting to know people and stuff, I got a poem that came into my head and that helped me say you know how, you know it got out some of my frustrations. She erm, they did some re, they were doing some research on a little machine called a sense cam. Erm, and she was one of the first pers, people who piloted it. And you know, it was found that it was really good, good for her. And erm, and I've got one now.

Actually, one thing I've forgotten to tell you, erm, Mum erm, has always been into sort of self help books and things and when I was sort of in my sort of really down period after my friend had died and everybody had gone away and stuff, erm she suggested I read this book that she'd read called "feel the fear and do it anyway" by Susan Jeffers and again, that was a, a turning point for me. Cos there was lots of things in there that just made complete sense. So I started watching the news to try and give me things that I could say when I was with people and didn't know what to say. It's this thing I have on my bedside table. Before I go to bed at night, I turn it over to the next day. And date so that when I wake up I know what day it is (laughs)

That's my daily tablets I take. So erm, I mean with things at home, it's a little bit easier. I mean you need to have sort of systems in place like in the kitchen, you know things have to be in a certain place or otherwise I won't be able to find it. And same in my room, really. I've got labels on the cupboards as to where my jumpers are. Whereas when I tended to work from home I spread everything out on the floor and talk to myself and sort stuff out you know. So and I can't really do that at
Revealing information

It’s difficult though with you know, how much to tell people when you meet them and stuff. Cos you don’t want them to feel sorry for you and treat you any differently but you also don’t want them to think, “Oh why’d she not remembering this?”

So it’s just sort of deciding how much to tell you know. I mean I still need you know I’d, I need to manage it and you make sure I’m doing what I need to do to do the job but I don’t wanna make you know make the biggest you know issue really so

I don’t know, I mean I had sort of various experiences you know if you, some people I’ve told them and they’ve backed off and you’ve never seen or heard from them again. And other people have, you know, patronized you and said, “Oh you won’t remember who I am will you. I’m so and so.”

Erm, I don’t, I think I’ve let them know and mum’s let them know I think cos she’s church warden and she’s good friends with a couple of the people on the church committee

Facial recognition

But I still need, you know struggle with, I can’t recognise everybody at work. Erm, I mean I’m okay with the team that I sit in the office with cos I see them on every day.

Erm, on the sort of days where there was people that were you know, there for a few days It was er, I had to sort of be honest and say sorry I haven’t. You know I’ve got memory problems. I can’t recognise you. And some of them were okay about it and others you know didn’t bother talking to you afterwards.
### Table 8: Narrative analysis table - Participant 3

#### 4. Roles

<table>
<thead>
<tr>
<th>Role / Issue</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Interview number / box number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worker role - See ‘Activities’</td>
<td>Erm, I wouldn’t remember anything about school-friends and things really. Cos erm, my best friend who I did my A’ levels with had leukaemia the same year that I had encephalitis. But sort of finding social outlets with people my own age was difficult. Cos none of them really understood why I couldn’t remember who they were or couldn’t have. Cos conversations were very difficult. Still is really cos you, you know people tell you things and you want to be able to remember them. So er yeah, I mean she was sort of the first friend as such that I, that I made up here and er, we started sort of going out a bit and seeing each other so it was nice. And I think she inspired me in terms of work as well cos you know she struggled with things and, you know, was stubborn like me. And you know persevered and got round things and I thought, “Well if she can do it, I can do it.” Started sort of, became a member and went to, they had a regular badminton session and stuff. I mean it’s a long way to go, cos it’s a good hour and a bit drive. Yeah. so that’s been a challenge to meet anybody my age really.</td>
<td>Social isolation exacerbated by death of friend</td>
<td>1 / 60 1 / 68 1 / 228</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social awkwardness</td>
<td>1 / 238-240</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Finding a new friend</td>
<td>2 / 884-892</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inspired by friend overcoming challenges</td>
<td>2 / 906-914</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social identity with people of own age</td>
<td>2 / 1668-1670</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Symptoms making social</td>
<td>2 / 1710</td>
</tr>
<tr>
<td>2. Being a member of the encephalitis society</td>
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<td></td>
<td></td>
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<td>---------------------------------------------</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Cos I mean I sort of going out drinking and going to nightclubs and things. You know I wasn’t. That was all too much so I didn’t want to do that. So er, cos I couldn’t really drink anyway and er cos of the tablets and things and and it was all, you know with the fatigue and things it was too much to stay out late at night and do that so it kinda altered that a bit you know.</td>
<td></td>
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</table>

| 3 / 948-962 |

<table>
<thead>
<tr>
<th>2. Meeting friends through the charity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Socialising with only family / parents</td>
</tr>
<tr>
<td>Social isolation</td>
</tr>
<tr>
<td>Confidence gained once friendships formed</td>
</tr>
<tr>
<td>Social representation of 'no friends'</td>
</tr>
</tbody>
</table>

| 1 / 341 |

<table>
<thead>
<tr>
<th>3. Friends with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>So er, I mean most of the, the friends I’ve got now are. There’s who I work with on the (work) scheme. She’s got a disability as well, so we can relate to each other. and I’ve met through the society. And er, I’ve still got two friends from er, school who keep in touch, but they’re the only ones from the sort of past that I’m still in touch with.</td>
</tr>
<tr>
<td>Yeah. I mean on that first retreat erm, there was three good friends that I</td>
</tr>
</tbody>
</table>

| 1 / 399-405 |

| Social group at fault not her difference |
| Finding friends through the charity |
| Comparison processes |

| 2 / 1574-1586 |

| 2 / 2128-2132 |

| 2 / 2148- |
made and still in touch with now.
You know at least I can walk and you know I don’t have to have people do things for me so it made me feel, you know put it into perspective really.
But I think er, you know that the society’s helped me cope with that cos I know, I know there’s other people and you know we all have different ways and we can help each other with you know, suggesting different things.
We try and keep in touch, either I go down there or we meet up somewhere up here, cos (friend) can’t get in here cos of her wheelchair and things so we have to meet somewhere more sort of central.
Right. Oh emm I mean me and (friend), we hit it off straight away when we first met at the retreat and I just, both on the same sort of level, personality wise and it’s just nice to catch up really and she’s sort of been a bit of a, bit of an inspiration to me really cos she’s you know, she er, she was working, she’d got two kids and everything.
Yeah. She was the sort of you know the person that helped me to laugh about the problems rather than take it deadly serious and be oh, stressed with myself.

<table>
<thead>
<tr>
<th>4. Issues of difference</th>
<th>Peer support</th>
<th>2150</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yeah. I mean most of my friends are up to an hour’s drive away. Er, the rest of them are, do tend to be older Younger people tended to want to go out and drink</td>
<td>Adapting social situations</td>
<td>2 / 2713-2715</td>
</tr>
<tr>
<td></td>
<td>Inspired by friends with disabilities – comparison processes</td>
<td>3 / 79-81</td>
</tr>
<tr>
<td></td>
<td>Taking life less seriously</td>
<td>3 / 106-107</td>
</tr>
<tr>
<td></td>
<td>Social isolation</td>
<td>3 / 141-143</td>
</tr>
<tr>
<td></td>
<td>Age difference</td>
<td>3 / 180-186</td>
</tr>
<tr>
<td></td>
<td>Normal activities at lifestage</td>
<td>3 / 2418-2431</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Daughter 1. Impact of her behaviour on parents</th>
<th>Mental health issues of frustration</th>
<th>1 / 337</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had quite a tough time with Mum and Dad. Where apparently I was, I mean I can remember getting very cross and frustrated with them easily and my moods were up and down like a yoyo Er, I used to get really vivid nightmares as well. I can’t really remember what they were now. But er, they were really scary. And I’d wake up screaming in the middle of the night. Mum said she got to a point where she just wasn’t getting any sleep. I don’t know you sort, it’s difficult cos me Mum and Dad you know said I wasn’t the same as I used to be. And you know I was, I found that difficult cos me and Mum had always been really close.</td>
<td>Emotional impact</td>
<td>2 / 180-186</td>
</tr>
<tr>
<td></td>
<td>Impact on relationship with mother</td>
<td>2 / 1832-1834</td>
</tr>
<tr>
<td></td>
<td>Symptoms of ABI impacting on family</td>
<td>2 / 1846-</td>
</tr>
</tbody>
</table>
You know we weren’t as close. But I still, I mean we, we are close but we’re not like we were before. Er, neither, you know, I can’t really put my you know a point on what, what’s different. But you know so that was hard to come to terms with.

2. Parents helping / helping parents

And I, I’d ring Dad and say, “Help. I don’t know where I am.” (laughs) which was rather scary.
So Dad became ‘Dad Nav’ (laughs)
Yeah. Yeah. cos I mean although you know Mum and Dad were such a great support and helped me through everything. I didn’t feel that they really understood what was you know what I was going through and how it felt.
I think, I don’t know, I think with my brother as well, you know, mum and dad have sort of come to rely on my you know, advise and stuff with dealing with things with him as well so it’s sort of mutual really. They help me out with things and I can help them out with things cos of my you know

Support from father 2 / 76-78
Support from parents 2 / 92
Issues of difference 2 / 1860-1862

3. Family activities

I was going to say I tend to go to Mum and Dad’s once a week. Tend to have Sunday dinner together and so
Yeah, we go to church and then have Sunday dinner together. Mm yeah, yeah. And Mum’s cooking so we tend to chat while she’s cooking or I’m helping her prepare something or yeah and talk about you know, or generally sort of talk about what’s coming up next week in the village if there is anything.

Family routine / support / shared activities 3 / 1837-1841
3 / 1851-1853
3 / 1959-1961

Sister

Cos my brother had been through erm, supported employment and he had all sorts of problems where they’d discriminated against him. When we’d had to speak up for him and I just thought, “There’s nobody there doing that” so wanted to looking into it a bit more.
So we spent quite a few weekends going to cheer him on
And there was, there was lots of little issues like that seemed to be cropping up and I just thought, “Oh you know if we weren’t here to help him, who would do this?”
Erm, no we go, he goes to a disabled swimming group once a fortnight so me and mum take it in turns to take him there.

Occupational persistence of helping 1 / 156-158
Family cohesiveness 2 / 14
2 / 725-729
Positive thinking 3 / 1999-2001
<table>
<thead>
<tr>
<th>Role</th>
<th>Statement</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>So I think it helps his self esteem as well to keep that sort of positive stuff. And that chap behind you which I realise I forgot to tell you about last time is my boyfriend. (laughs) and he came, you know, er he was with me the other weekend so he came down to meet them. And er my other friend through the society knew him and she did some matchmaking cos she thought we were both perfectly matched. Er, about every other weekend at the moment so I go down to him and he comes up to me so.. CB - Right. Yeah. That's good. Okay, so has it made a difference to your life having a significant other in Yeah. Definitely. Yeah. Very much.</td>
<td>3 / 2029-2031</td>
</tr>
<tr>
<td>Church protection rep</td>
<td>I'm the child protection representative cos of my link with social services previously and you know. And er, I have to do sidesman duties you know at church sometimes and getting the teas ready and things like that. Erm, I've always enjoyed volunteering and helping out you know and things so nice to sort of feel like you know you're helping and needed so, yeah. Yeah. so since I've been going out with [REDacted] (boyfriend) I've let my er church duties slip a bit really so so I'm feeling a bit guilty about that one. (laughs) Cos I'm you know not here a lot of the weekends.</td>
<td>3 / 147-153, 3 / 163, 3 / 185-187, 3 / 196-201</td>
</tr>
<tr>
<td>Cat owner</td>
<td>Yes, they generally have my, I have cereal for breakfast most mornings and they like the milk so that’s them having the milk. Yeah. Uuhh. Yeah. I mean we've always had cats as a family, or a cat and er, I missed having one, you know when I was living on me own so felt like I needed one. Well, they're good company. It's funny they, you know they seem to know when you're, when you're not very well or or when you're, when you're feeling a bit stressed out or something, cos whenever, you know if I get stressed with work and stuff the cats’ll always come</td>
<td>3 / 1364-1368, 3 / 1374-1384, 3 / 1388-1392</td>
</tr>
</tbody>
</table>
and jump on me lap.

Charity Worker: And learning about erm, kind of support people would need and things, bereavement and stuff cos some people, you know die of it and dealing with families for that, erm, learning about how to appeal you know, get cons, er challenge consultants if they've not diagnosed it properly and things like that. Erm, well to be honest, I'm struggling with it at the moment cos work's so busy and I don't really feel I've you know, got the energy or time to give to it as much as I would like, to the society really. And I think, I don't know I've always enjoyed helping other people and I think sort of sharing how it affects me and how I get round things, helps them as well so yeah. I feel positive about doing that so yeah.

| Occupational persistence of caring | 2 / 2238-2246 |
| Prioritising tasks               | 2 / 2280-2288 |
|                                  | 3 / 1088-1096 |
### Table 9: Narrative analysis table – Participant 3

#### 5. Activities

<table>
<thead>
<tr>
<th>Activity / Issue</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Interview / Box number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Work</strong>&lt;br&gt;1. Theme of helping / problem solving / people</td>
<td>Cos I’d intended after my ‘A’ levels to go to university to do Occupational Therapy you know I was still interested in psychology and sociology and stuff and that included all of that, so I transferred into the second year cos I’d passed all the first year academic side. &lt;br&gt;the dissertation I did for Uni was around people with learning disabilities and supported employment and whether they needed advocacy to help them speak. &lt;br&gt;Cos my brother had been through erm, supported employment and he had all sorts of problems where they’d discriminated against him. When we’d had to speak up for him and I just thought, “There’s nobody there doing that” so wanted to looking into it a bit more. &lt;br&gt;At first they put me at er, I was in a sort of reception type job. And I didn’t really find that very you know enthralling (laughs). So I and er, I asked to change and go onto something a bit more people centred &lt;br&gt;Er, where did I go after that? Oh yeah I went to a housing association as a housing support worker, sort of visiting people in their own homes and helping them with paperwork and bills and things like that. &lt;br&gt;So I was looking for something else. And then I got the job at erm Social Services as a community care officer. And er, that was a challenge (laughs) &lt;br&gt;I like being around people erm, and just I guess you know, I’d seen enough sort of injustice with my brother and helping other people to sort of get their rights and things just you know, you know motivated me really.</td>
<td>Occupational persistence of helping others</td>
<td>1 / 64 1 / 146-148 1 / 154-158 1 / 168-170 1 / 190-192 1 / 198 2 / 780-788 2 / 955-957 3 / 2045-2047</td>
</tr>
</tbody>
</table>
I don’t know, I just, it didn’t really feel like it was going anywhere. I guess I’ve always been quite an ambitious person. I wanted to sort of have a bit of progression. No I think that was there before. I think that’s always been there. Yeah.

but I also had my own system with things on the computer of what I’d done with who and when. So I could keep track. And worked from home half a day a week just to keep on top of those kind of systems. So, which worked reasonably well. Again, I still, still have challenges at work. I’m not sure how, how much people are aware of it or not cos I admit, I mean you know I was, I’ve been honest and told them about the difficulties. Erm, and again I had, when I first started there I had half a day at home. But I still need, you know struggle with, I can’t recognise everybody at work. And I’m a bit, I don’t know, I guess I’m a bit anxious now about sort of making a big issue of it cos when people focus on it I think it makes it worse. But I haven’t had, cos in my job that I’m in now, erm, I sort of got a bit of a promotion last year and I started off as a community care officer, then got promoted to community care manager last year and it’s a much more involved role and I haven’t got as much spare time as I did when I first took this on, you know, they’ve asked me, you know but er, it’s difficult really cos you feel like you’re being criticised.

Whereas when I tended to work from home I spread everything out on the floor and talk to myself and sort stuff out you know. So, and I can’t really do that at work. So I can’t, I don’t feel I can concentrate and focus on the strategies and stuff I’m trying to use.

but I also had my own system with things on the computer of what I’d done with who and when. So I could keep track. And worked from home half a day a week just to keep on top of those kind of systems. So, which worked reasonably well. Again, I still, still have challenges at work. I’m not sure how, how much people are aware of it or not cos I admit, I mean you know I was, I’ve been honest and told them about the difficulties. Erm, and again I had, when I first started there I had half a day at home. But I still need, you know struggle with, I can’t recognise everybody at work. And I’m a bit, I don’t know, I guess I’m a bit anxious now about sort of making a big issue of it cos when people focus on it I think it makes it worse. But I haven’t had, cos in my job that I’m in now, erm, I sort of got a bit of a promotion last year and I started off as a community care officer, then got promoted to community care manager last year and it’s a much more involved role and I haven’t got as much spare time as I did when I first took this on, you know, they’ve asked me, you know but er, it’s difficult really cos you feel like you’re being criticised.

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Well maintain, well that’s not true, we had a new manager start, who didn’t like people working at home and he stopped it. And er, I did go through a difficult phase where I wasn’t managing things and I was forgetting things and people were
noticing you know that I wasn’t keeping up. And er, he wasn’t supportive of that at all, cos he said, “You’re in a management role now.” Whereas this one that I’ve sorted of started last year, I haven’t really had the opportunity or time to be able to you know, firm up the strategies and I feel like I’ve been through about ten thousand of them since last June you know. So I keep trying different things and it’s not working and then going back and trying a different way.

Coping strategies
1. Cognitive strategies
She’d got me trying three different ways of remem, trying to remember people. One was just purely recognition doesn’t work very well. Erm, the second one was to think of three things that I knew about the person and write them down and the third one was I’d got to try and link something about what they look like, to their name or something. But with you know, work situations and social situations I didn’t find it as easy cos you know you’re not, don’t always see people every week and er, it’s hard to sort of use those strategies without feeling totally stupid. (laughs) And I am worried you know, conscious about it

2. Implementing them
We can’t do that. Erm and er, you know I wanted to make notes during the session so I could remember what had happened and stuff and again they say it’s not gonna work with this client group. You can’t do that. Erm, you know and I said even if I explained and said you know what difficulties I have - they have those problems. I have these problems. They just wouldn’t let me do it. They said it was unprofessional. She put quite a lot of pressure on and er, didn’t really, I don’t know that she fully understood the difficulties I had. She er, criticised me when I didn’t manage sometimes. And er you know I found that quite difficult.

It becomes plainly obvious that my strat, you know I’m not using my strategies. You know it just takes so much time and You know you get in and you think “oh I really should do that but I’m tired and I want a rest

Allowances not given
Requires time to organise strategies
Impractical to implement coping strategies
Irony of chosen vocation
Undeserved criticism
Constant requirements to use strategies
Fatigue
<p>| | | |</p>
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<tbody>
<tr>
<td>3. Labelling</td>
<td>I mean at home, I quite often label everything, so I know where things are.</td>
<td>labelling</td>
</tr>
<tr>
<td>4. Diary</td>
<td>Er, diary’s essential. (laughs) Do rely on a diary on a day to day basis just to know what’s coming up next. Me diary and messages really that help me get through it and writing a daily diary helps cos, because I’m writing it down, I’m more likely to remember it. I know I did something but I’ve got no visual memory of it and I can’t picture it or hear or see anything about it. But my verbal memory I you know if I’ve written it in my diary, I know I’ve done it. Tends to be more, mainly factual about what’s happened during the day. But you know if there’s something particularly emotional I write about that so Yeah. cos I do, I do use them to sort of retrieve memories and stuff at a later date when you know, if I need to go and check when something happened or I’ve got, I’ve got a drawer full of them. I’ll go through my diaries to see what, what happened when.</td>
<td>Diary</td>
</tr>
<tr>
<td>5. Sat Nav</td>
<td>Until I eventually got a sat nav which is the best invention ever (laughs), cos I can find my way round without worrying about it now. Cos you know I used to dread you know if any friends asked me to go anywhere, cos I you know cos I’d have to go through all that and say, I couldn’t just go, you know they couldn’t ring me up on the afternoon and say, “do you fancy coming here?” Cos if I hadn’t got an hour or so to plan it and do it you know I’d have to say, “Oh no sorry I can’t make it today”</td>
<td>Orientation in space</td>
</tr>
<tr>
<td>6. Indexing</td>
<td>And I’d got again, using the index cards I used erm, you know put So that I could you know, know next time I needed to contact them again. different organisations, key people I’d spoken to</td>
<td>Organising</td>
</tr>
<tr>
<td>7. Watching the news</td>
<td>Cos I watch the news most days and I used, I never really used to be interested in the news when I was sort of growing up and I always thought it was boring and stuff. When I was sort of finding it difficult to make conversations and get to know people, sort of listening out for what other people were talking about and quite often it was what was on the news or something. So I started watching the news to</td>
<td>Social awkwardness</td>
</tr>
</tbody>
</table>
try and give me things that I could say when I was with people and didn’t know what to say. And it’s only really you know with new people or when I’m stuck for conversation.

8. Sense cam

And sort of use it for social events or other things. Can’t use it at work. I mean it’s not appropriate to wear it at work anyway and er, you do get some funny looks when you’re walking round town and stuff.

Yeah, you plug it into the computer and review the photos at the end of the day. So we’ve both got laptops so we sat there and do it together and made notes. Because when, before you know when I used to go and do things, I mean I’d write in my diary what I’d done and that but I’d got no vision of what it was like cos you know it just sort of goes out of my memory I can’t sort of picture it in any sense. I mean, one of the things I think would be better with it for me would be if you’ve got voi, if you had a sound, you know something that you could speak into

9. Necklaces

And those necklaces that we’ve got on, we made together. So she knows who I am and I know who, if we’re out somewhere and there’s lots of people around.

10. Bedside calendar

It’s this thing I have on my bedside table. Before I go to bed at night, I turn it over to the next day and date so that when I wake up I know what day it is (laughs), yeah. Cos otherwise I wouldn’t know what day or date it was Bank holidays sometimes throw me with you know, with the normal working week.

11. Birthday book

I’ve got all me friends and family birthdays in and I tend to look at it at the beginning of each week to see if I’ve missed anybody’s birthday.

Socialising
- See ‘Roles – Friend’

Charity Involvement
- See ‘Roles’

Driving

Yeah. And I mean the, the sat nav’s just a godsend cos it was always so stressful and you know, trying to plan anything beforehand. Having to go on the computer the night before and write all the instructions out and
<table>
<thead>
<tr>
<th>Writing poetry</th>
<th>Poem as self-expression</th>
<th>2 / 1888-1904</th>
</tr>
</thead>
<tbody>
<tr>
<td>And when I was at university and struggling with friends, I got a poem that came into my head and that helped me say you know how, you know it got out some of my frustrations and helped me sort of just write down how I felt. I've found that when I've been struggling with something or I've been really sort of down about something it comes out in a poem. (laughs) or when I'm you know happy as well. And there was a couple of people who said that's you know, that's really helped me to understand what it's like now. Cos a couple of them knew somebody who'd got it and hadn't really understood what it meant so served its purpose, which is good.</td>
<td>Helping others</td>
<td>3 / 2526-2532</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Church goer</th>
<th>Priorities</th>
<th>3 / 1534-1540</th>
</tr>
</thead>
<tbody>
<tr>
<td>So and you know some sarky comments from some of them about, “Oh where were you?” But er, you know, they, they most of the people at church know about my prob, memory problems so that wasn’t too bad. Yeah. So since I've been going out with ***I've let my er church duties slip a bit really so so I'm feeling a bit guilty about that one I mean I never really went, well I didn't go to church much in the latter years in ***Cos it, I mean I think I stopped going to church when I was about fourteen or so I think that it just got, I don't know, they weren't the friendliest group down there. And I sort of lost a bit of faith really. And then er, after er, ***my friend died and stuff, after and I sort of felt like I wanted to go a little bit Erm, I don't know, a sense of belonging I suppose.</td>
<td>Sense of belonging in church</td>
<td>3 / 1875-1879</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Tap dancing / keeping fit</th>
<th>Social isolation</th>
<th>2 / 1559-1566</th>
</tr>
</thead>
<tbody>
<tr>
<td>Er, I thought I'd try something else and then I, what did I do after that? I joined a keep fit group, just trying to think where that was now. Whether that was here in the village or somewhere else. Went to that once a week. I mean that was okay again, but it, you know you just went and did that really. Didn't really make any friends it other than to say 'hello' at the night. Now I mean I do tap dancing in the village hall. I tend to go for walks and things you know. There's a nice sort of loop round the village which er, I can do now. When I, I mean when I first moved up there was no</td>
<td>Enjoying countryside</td>
<td>3 / 2271-2273</td>
</tr>
</tbody>
</table>
way I could have done that cos I've have been totally disorientated
Gets rid of a bit of energy er, social as well. I mean I struggle with who’s who.

<table>
<thead>
<tr>
<th>Reading self-help literature</th>
<th>Positive thinking</th>
<th>3 / 1931-1933</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yeah. Yeah. I mean I don’t know really. I mean being sort of with the positive thinking you know books and stuff that I read and that and I can relate that to sort of religion now. You know cos it all seems to sort of hang together</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>He’s actually, that’s er, normally I see him about once a week but I haven’t this last couple of weeks cos he was busy socially at the weekend and I was. I was going to say I tend to go to Mum and Dad’s once a week. Tend to have Sunday dinner together and Yeah, we go to church and then have Sunday dinner together.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix K

**Table 10: Narrative analysis table - Participant 3**

<table>
<thead>
<tr>
<th>Issue</th>
<th>Dialogue</th>
<th>Themes</th>
<th>Int. / box number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport</td>
<td>I mean that’s one of the reasons why we’re, me and me boyfriend are talking about moving away somewhere else. He doesn’t drive and he would be very isolated here.</td>
<td>Poor transport links</td>
<td>3 / 1679-1681</td>
</tr>
<tr>
<td>Recognising people</td>
<td>Erm, I mean I, if there were more people around and stuff, I’d probably worry more that I knew them and that I was ignoring them and so I find it easier living here than I did in [redacted]. Don’t, I don’t know, guess it’s the fear of you know, bumping into an old school-friend and not having a clue who they were or Yeah. cos I mean I di, apart from my best friend [redacted], I didn’t really remember any of my school friends and stuff yeah.</td>
<td>Social awkwardness Social isolation</td>
<td>3 / 679-683 3 / 695 3 / 711-715</td>
</tr>
<tr>
<td>Friendlier people</td>
<td>And started getting and you know when we moved up here, this church was so friendly and welcoming and it was very nice to, to go and then I , I got confirmed about oh it must have been a couple of years after I moved up here. Erm, when I compare it with living in sort of [redacted] and near [redacted], I feel like I’m I don’t know, more of an equal sort of member of society up here. Whereas down there it felt like everybody was judging me. Cos you know people are so busy and you don’t get the I don’t know, they just seem more friendly and sociable up here than they did down there so I don’t know.</td>
<td>Welcoming church Social identity Close rural community</td>
<td>3 / 1881-1883 3 / 2883-2893</td>
</tr>
<tr>
<td>Location to family</td>
<td>It’s yeah, it’s my parents and my er, my brother as well. Cos he’s got a learning disability and difficulties and I don’t, I wouldn’t want to be too far from him and cos he relies quite heavily on my support as well.</td>
<td>Family cohesiveness</td>
<td>3 / 601-605</td>
</tr>
</tbody>
</table>
Appendix L  Example of participant photographs

Participant 3, Angie
Appendix M

Table 11: Example of photographic analysis – Participant 3, Angie

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observation of data as a whole – (overtones, subtleties, connecting and contrasting patterns)</td>
<td>Pattern seems to be around life associated with coping strategies and friends met through the charity. A strong social element and time spent with friends is apparent, as the inclusion of her parents’ home.</td>
</tr>
<tr>
<td>Feelings and impressions (and to which particular photos do they belong to?) [Reflexive perspective]</td>
<td>Much of P3’s life appears to be intertwined with the things related to her medical condition and it must exert a strong influence over how to cope with daily life and network with friends.</td>
</tr>
<tr>
<td>What questions do the photographs bring to mind?</td>
<td>P3 expressed a warmth and strong connection with her friends met through the charity and the photographs show they are an important part of her life. However, she did make the point that all of her friends were either people who had disabilities or much older and held regret at finding it hard to meet people her own age, who had similar interests. Does she see this as a missing element in her life?</td>
</tr>
<tr>
<td>How do you respond to any cultural drama i.e. do you have comments about the context of where they were taken and by whom?</td>
<td>Main strands of social and coping, with the support element of her parents’ home.</td>
</tr>
</tbody>
</table>

**Stage 2**

[Realist perspective]

Log general content
- activities e.g. self-care / productivity / leisure
- people included
- temporal considerations

Outdoor activities – social but also her friend was undertaking research on the outdoor walk, therefore both recognize the importance of helping.

Indoor social i.e. drink with friends. Leisure.

Many involve how she uses coping strategies and the everyday tools that are essential just to maintain her orientation and memory so as to hold down a job. The photograph of the packed workbag indicates a very busy workload.

Significance of her family.

[Contextual perspective]

Contextual comments on this content

English, middle class, rural / relatively quiet. Has pets for comfort. A social
<table>
<thead>
<tr>
<th>Being, with many of friends having disability also. Coping strategies play a significant part in her life.</th>
</tr>
</thead>
</table>
| **Stage 3** – structured analysis  
What does this add to the narrative analysis? (presentation of self in the narrative)  
What does this add to the analysis of narrative? (themes etc. either within the set of this participant’s photographs or across sets of participant photographs) |
| The support structures in place i.e. family, friends met through charity, pets and most significantly the day to day coping strategies she has to employ, that are very time-consuming and tiring.  
Charity–involvement - helping with research.  
Importance of support structures. |
| **Stage 4**  
Are there any overtones and significance of details? (lay out the set of photographs in entirety to produce conclusions) |
| Most activities in one way or another are strongly influenced by her status as someone with an acquired brain injury, either through the user of the charity or coping mechanisms. |
## Appendix N

### Table 12: Example of coding frame for analysis – Participant 3, Angie

<table>
<thead>
<tr>
<th>Participant number and pseudonym</th>
<th>P3 Angie</th>
</tr>
</thead>
</table>
| **1. Positional aspects**        | I had first met Angie at an event when I did a presentation on my research and she had expressed an interest in taking part. I was therefore surprised when she checked who I was when I called at her home at the pre-arranged time. This was an example of her hidden disability of prosopagnosia, (face blindness), which is at the centre of coping with daily living.  
I was worried that she may not be able to give her life story, with having little memory before age 18. However, I was impressed by the extent of her coping strategies, for example the diaries she had maintained over the years, as a written memory of her life. She talked about not being able to fulfill her dream of being an occupational therapist and not being allowed to implement her coping techniques during practice placement as a student. I empathised with this situation as I see this happen with my own students and feel helpless at times and maybe I should rethink the adjustments we make for students. I felt that I wanted to reassure her that the type of role she currently held was indeed similar to many that occupational therapy graduates apply for now. It struck me that she would make an excellent occupational therapist when she described her life and the experience of implementing so many coping techniques.  
Overall, I was struck by how she carried a sadness about the small social circle she had, yet in actual fact it is probably as big as the average person’s. Perhaps this was due to many of her friends also having disabilities and perhaps this was an issue of feeling socially excluded from many non-disabled groups. |
| **2. Context**                   | Angie is in her late thirties and lives on her own in a small rural village. Her family live nearby. She grew up in an urban environment some distance away from the area where she now lives. When |
Angie was seventeen she became ill following a holiday in Spain, she fell in to a coma and was eventually diagnosed with encephalitis, resulting in an acquired brain injury. The symptoms of the injury include propagnosia, (face blindness), sequencing problems and memory loss, as well as changes to her sense of taste. She holds little or no recall of her childhood. Her career aspirations to be an occupational therapist were thwarted but she did complete a degree. She has always worked in the health and social care sector, currently in a management position. She is independent in most aspects of her daily life and draws on numerous coping strategies to enable this.

3. Narrative tone; Optimistic / Objective / Pessimistic
Angie’s narrative tone appears to be pessimistic as opposed to optimistic. This may be due to the impact of a biographical disruption during her adolescence. She grew up with supportive parents and describes her mother as very practical and her father as impatient. She was close to her brother who was born with cerebral palsy. Her mother worked in a special school and she always wanted to be like her mother, which led her to look for a career in a helping profession. She holds little recall of childhood events or her life prior to the brain injury at age seventeen. Having seen her brother cope in life with his disability inspired her to find ways to cope with her own.

She describes her life as being a little boring, as she is not able to be spontaneous; going to new places involves preparing carefully. She uses poetry as a release of emotions and has had some of her poetry published by the charity with which she is involved.

3. Narrative structure; Progressive / Stable / Regressive
Angie’s narrative is stable up to age eighteen from what she is told, but she recalls little of it. Her memory and recognition difficulties from age eighteen had a huge impact on her social interactions with her peers, as she was no longer able to recognize them and recall information about them that is typically incorporated into everyday conversation. She could no longer socialize in the evening due to fatigue and developed a dislike of alcohol due to her taste being affected, which meant her former friends had little in common with her. This resulted in her becoming increasingly frustrated with life and unable to make sense of what was happening to her. Her relationship with her parents deteriorated and although they remained close her mother questioned who she had become. This caused her to lack confidence in everyday interactions and she questioned her own identity. It was also a time her closest friend died and she went through a period of having panic attacks, nightmares and depression, demonstrating the emotional impact of biographical disruption.
University life was difficult for Angie as she was discontinued from her chosen vocational programme, she thinks because she wasn’t given enough opportunity to put her coping strategies, such as additional note taking, in to practice. She also struggled to make friends there. She was heartbroken at this loss of career. It was at this point that she returned to poetry as a means of expression of emotions. A doctor told her that she wasn’t capable of achieving a degree, but she did in fact go on and achieve a non-vocational one.

After university, a period of unemployment followed, which she used to gain work experience by volunteering. She found that she didn’t enjoy administrative work whilst volunteering and switched to gain experience that involved helping people, as this was what she had wanted to do if she had completed her occupational therapy degree. She moved with her family to a small rural community a few hundred miles away from where she grew up. She took a job with an advocacy organization, which she loved as it involved making a difference to people’s lives. Eventually the funding dried up and she was looking for work again. More social care work followed and one employer offered the opportunity to take some time out. She capitalised on this and moved to Australia and New Zealand for six months. This gave her the opportunity to meet new people on a daily basis, which eradicated the need to remember details in social interactions and she quickly gained self-confidence.

Over the years Angie has found books written by inspirational people who have overcome adversity helpful in coping with her own life. She describes reading one of these books as making complete sense.

In more recent years Angie has learnt to take care with whom she reveals her disability to as it can become the main focus of interactions, to her detriment and this has happened in the workplace before. She utilizes a vast array of coping techniques to aid memory and recognition and positive thinking and affirmations to overcome what she calls ‘negative chatter’. She describes being introduced to the Encephalitis Society as a turning point in her life; she met people with similar issues who understood what it must be like with a similar illness experience and has become inspired by some of the friends she has made. This was the first time in years that she felt that she wasn’t abnormal and feels no social awkwardness when with the friends she has made through the
organization as they understand. Also for the first time she met another person with the symptom of prosopagnosia and she was able to connect with them and become good friends. As a result she volunteers for them now.

From this point onwards the narrative was able to move forward and Angie was able to stop being angry and putting herself down. She discusses this as a turning point. She met people who she considered to be far worse off than herself, yet had a positive attitude and this inspired her. However, today the narrative appears stable, with no climb to a progression as there are still many issues to deal with. She has an intense daily routine of managing her own coping strategies and being careful who she reveals her invisible disability to, so as not to experience prejudice, especially in the workplace.

<table>
<thead>
<tr>
<th>4. Activities and roles at stages of the life story</th>
</tr>
</thead>
</table>
| As far as Angie can remember she had a normal teenage life, socializing with friends and had her first independent holiday with a friend at 17, which is when she became ill. She had grown up with a disabled brother in the house, which influenced how she saw disability by way of being inspired to achieve in spite of it. She also wanted to be like her mother and her mother had worked with people with special needs.

When Angie was in hospital she became friends with a women who wrote poetry about her illness and realized that poetry can be a means of expression and so adopted this activity herself, especially when she had a difficult period coping academically and making friends at university some years later and re-engages with writing occasionally now to share with other people with encephalitis.

When she was discharged from hospital coping with daily life became a challenge as she didn’t recognise once familiar people and experienced memory problems. This led to anxiety and panic attacks. This led to a referral who to a psychologist who diagnosed the prosopagnosia and introduced some interventions.

As sequencing was now difficult, due to executive functioning difficulties, she had to write instructions of how to carry out tasks. She was giving special learning support at college and eventually began
Angie put her coping strategies into place in health and social care practice situations, which were a key element of the programme.

Employment opportunities have been taken up around social care, pursuing her desire to be involved with a helping profession. There is a dissonance between wanting to have work that challenges her and managing cope with certain aspects of roles due to memory and sequencing issues and requiring additional time to cope at times. This can cause relationship issues in the workplace. She describes past work place environments as ‘quite a challenge’, due to pressure from managers. Stress caused when she feels she is getting behind amplifies the issues, as it increases her cognitive difficulties. She is reluctant to let people in the workplace know about her disability in case it encourages pity or discrimination.

Today she has drawn up lots of lists about to sequence everyday activities, such as using the washing machine. She keeps a daily diary so as she recall details about her life other people may draw from their memory. She watches the news on a daily basis to make ready conversation with people at work to cover up for not remembering details about them personally. A sat nav is invaluable to her in order to make her way around in the car or on foot. Calendars help to orientate her to days of the week and up and coming events, none of which she would remember if not recorded. She arranges to wear similar jewelry to a friend so as they can recognize each other. She still sometimes writes poetry to express her emotions. She has tried using a machine called a 'sense cam' that visually records what she is doing and she plays it back afterwards for recall. Cupboards in her house are labeled as to contents for ease of finding things.

Angie has a routine of full time work and engagement in her coping strategies of diary writing etc. She eats with her parents once a week and attends church with her parents. She continues with her trait of helping by taking her disabled brother to a swimming group, to help with his self-esteem.

| 5. Formation of any identities | Angie uses the imagery of the word, “Bye” to describe her hospital discharge and to suggest that she was no longer under any health service care because she was physically well, yet she was a long |
Angie felt like the same person inside and still felt like her pre-injury self. She began to ask herself the question, “Well who am I?”

When Angie was told that she wouldn’t be able to continue on her chosen university course she felt heartbroken, as it was a career she had always wanted to follow.

She describes herself as having fighting spirit, inspired by her brother’s achievements. However, she found that she was not supported on her chosen university course and was asked to leave due to a number of incidents that were due to her memory and recognition issues. She describes this as heartbreaking. She did achieve a degree, but was not able to become an occupational therapist as she had hoped.

Angie took her A Level exams before her brain injury but put her poor achievement down to being distracted and spending time helping her best friend who was terminally ill. This demonstrates the beginning of a pattern of helping others in her life.

Since her brain injury Angie has made several attempts at joining social groups, but found it difficult to meet people whom she felt had the same social needs. Social situations could become awkward.
interpersonal relationships) as she could never people or details about them to make conversation. She was unable to be spontaneous and if established friends suggested an outing it would take Angie hours of preparation to work out such as a route to get to a venue. She felt that the symptoms led to her being at a social disadvantage and led to losing these friendships. She felt socially isolated. Whilst she was able to go places with her family social opportunities with her peer group evaded her, especially as she didn’t like drinking alcohol, as a symptom of the ABI was alcohol now tasting foul and consumption of alcohol often being at the centre of social events for her age group. Additionally every social event was like walking into a room full of strangers and she couldn’t remember details about friends to make conversation with them.

Over the years health professionals have suggested strategies to overcome the propopansogia in social situations, such as making notes about people when they tell her things. But this is not practical as it draws attention to her and singles her out as different, again causing social awkwardness.

In more recent years Angie has learnt to take care with whom she reveals her disability to as it can become the main focus of interactions, to her detriment and this has happened in the workplace before. She utilizes a vast array of coping techniques to aid memory and recognition and positive thinking and affirmations to overcome what she calls ‘negative chatter’. She describes being introduced to the Encephalitis Society as a turning point in her life; she met people with similar issues who understood what it must be like with a similar illness experience and has become inspired by some of the friends she has made. Some of new friends have much greater issues to deal with and Angie has drawn on comparison processes to use this help her cope and move forward. They have also encouraged her to use humour as a way of coping too.

It has made a significant difference to her life having a partner.

<table>
<thead>
<tr>
<th>7. Any shared social stories; c) anchoring – concepts given meaning by</th>
</tr>
</thead>
<tbody>
<tr>
<td>She found the rejection from university education to be an occupational therapist ‘heartbreaking’, which emphasizes how it was seen as an interruption to her envisaged future life script. She describes her lack of challenge to the university’s decision down to not being strong enough to ‘fight’</td>
</tr>
<tr>
<td>connecting to the familiar</td>
</tr>
<tr>
<td>d) objectification – concepts acquire meaning through association with everyday phenomena</td>
</tr>
<tr>
<td>8. Occupational theoretical concepts</td>
</tr>
</tbody>
</table>
occupational therapist may have advised her to engage with. This is also reflected in her series of employment roles over the years and the volunteering activity she does for the brain injury charity.
Appendix O

Example of narrative analysis – Participant 3, Angie

Angie was born in the 1970s and grew up in a large urban town. Her family consisted of her mother, father and her older brother, Jack. The family was close and together they spent time supporting Jack, who had cerebral palsy, at events such as the Special Olympics, where he was a swimmer. Angie’s mother had had her children relatively young and as Angie watched her mother mature into an adult she hoped that one day she could be like her and do the things that she did. Her mother worked in a school for children with special needs and this, coupled with her experiencing life with a brother with similar needs, led Angie to make the choice of a future career that involved helping others. Her brother sometimes struggled with a number of issues and the frustration led to unexpected outbursts that the family had to deal with and Angie came to develop a strong dislike of conflict.

Angie decided to stay on at school to study for her A’ Levels and set her heart on becoming an occupational therapist. When she was in the upper sixth things didn’t go to plan; her best friend became ill with leukaemia and she was also distracted from her studies with her first boyfriend. As soon as her exams were finished she and a friend headed off to Spain for their first independent holiday. The day after she arrived home she began to feel quite ill. Her parents took her to hospital and it was some time before the medics were able to confirm a diagnosis. Eventually it was decided that Angie had encephalitis and she slipped in to a coma. On her eighteenth birthday she came round from the coma and Angie’s life had changed forever.

Her parents were naturally anxious, thinking what would Angie be like when she regained consciousness, if she regained it at all. Angie was unable to speak but when she began to use sign language, (she had learnt this before her A’ Levels) her mother was relieved as it was an indication that she could make herself understood and that she would be alright. Gradually her speech returned but what was apparent was that Angie was struggling to remember anything of her former life and that she was struggling to recognise even familiar people. Once physically well enough she was discharged from hospital with no follow up care on offer.
Angie did not gain the A' Level grades to get her onto her chosen occupational therapy programme, so returned to college to attempt study again. Her tutors were supportive and understanding of her need for extra time and helped her through to gain the required grades for university the next year. At home, life became quite difficult. Most of Angie’s friends had left for university and her best friend had subsequently died. Still being unable to recognise people, Angie’s remaining friends became distant: she tried to involve herself with social engagements but the memory issues meant that she didn’t remember facts about her friends and social situations became awkward. The encephalitis had also resulted in a change to her sense of taste and she no longer liked the taste of most alcoholic drinks. Coupled with fatigue, this resulted in her not being able to take part in nights out, that her friends typically engaged in as young adults. If a friend suggested going places it became awkward for Angie as she had no sense of direction and it would have meant having a lead in time to an impromptu event, as she needed to plan a route and make notes about how to get there and get home. She found it embarrassing going out in the town where she had grown up as she didn’t recognise familiar faces from school and elsewhere. The difficulties led to Angie not really understanding what was happening to her and why she was no longer in control of her life. She began to become frustrated which led to emotional outbursts and clashes with her Mum and Dad, with whom she had been incredibly close. Afterwards she would feel guilty at her behaviour, as she had seen this happen with her brother and didn’t want to do this to her parents. Her Mum began to tell her that she’d changed, which made her even more frustrated as she felt like the same person and couldn’t understand why they were saying this to her. She’d always kept a diary and began to look in her diaries for clues as to the person she used to be but this gave her no answers. She began to ask herself, “Well if I’m not the person I was before the encephalitis then who am I?” She had always looked up to her mother and wanted to emulate her and this led to her feeling enormously disappointed in herself.

She entered a period of depression and panic attacks at home which led to her being referred to a neuro-psychologist undertaking research. The psychologist administered various tests to precisely diagnose Angie’s cognitive difficulties and devise some additional coping strategies. Angie was diagnosed with deficits in her memory, sequencing and a perceptual difficulty called prosopagnosia or
face blindness. She was advised to try a number of strategies, such as repetition, making notes and inventing funny names in her head for people she met regularly. Some of the strategies worked but life was still difficult and often socially awkward; it seemed unnatural to make notes in social situations so she generally refrained from doing this.

She went off to university where the problems continued. Arrangements were made for her special educational needs and she began to experiment with coping strategies of her own. Academically the programme presented challenges but these were overcome. It was when she found herself in professional practice situations that she came up against barriers. She was struggling with recognising patients and asked if she could implement her strategies, such as making extra notes during patient interactions, but the educators seemed unsupportive and she was eventually asked to leave the programme. This was heartbreaking for Angie as her dream was to become an occupational therapist. The emotions at the time meant that she didn’t have the strength to challenge the system and she agreed to transfer to an academic programme of study that didn’t involve placements with patients. The prosopagnosia continued to cause her problems and on one occasion compromised her safety: she was walking in the city centre and saw a man smile at her so, being a friendly person, she naturally returned the smile, assuming she knew him but didn’t recognise him. He approached her and invited her to go along with him and she suddenly asked him, “Do I know you?” and he replied that she didn’t. When she thought about the possible consequences of a young female going off with a male stranger she was quite shocked. Other issues emerged such as becoming anxious as to whether or not she had locked the door on leaving the house and she found that ‘negative chatter’ made her constantly put herself down.

Being unable to express exactly what she was experiencing was a familiar feeling for Angie. When she was in hospital a fellow patient had given Angie a poem she had written to express how she felt. Angie decided to try this as a technique and found that it allowed her to capture her frustrations more readily than natural spoken word. She wrote a poem about her time at university and this did indeed help her.
During her final year at university her parents decided to move some distance away to a small rural village where they had enjoyed family holidays over the years. Angie moved to be with them, as she was someone who had always helped her mother with her brother Jack. Jack was in supported employment and making progress. They found that some of his colleagues were given pay rises whilst he was overlooked and this sparked the family to develop advocacy skills to right this injustice. This led Angie, now unable to be an occupational therapist, to follow this route in her career. After volunteering and gaining experience, she took a job as an advocate, which she thoroughly enjoyed. The volunteering had been especially helpful to her as it allowed her to test out what she was still capable of in terms of work, rather than being unrealistic and she had lost much of her confidence due to recent experiences. The element of helping others was extremely important to her. At the same time she developed more and more strategies to try and help herself. She found that the diary writing had become essential, to allow her to have an idea of what she had taken part in in the recent past. But social situations continued to pose a problem. Now living in a new area she came across few people her own age and when she did she no longer wanted to do the things that they typically did, such as socialising that involved drinking alcohol (which had an unpleasant taste now). She tried joining a local squash club but the members seemed reserved and competitive. She developed a friendship with a woman she met whilst volunteering who had cerebral palsy. She saw her as an inspiration as she was someone who overcame barriers put in front of her, which Angie could model. She enjoyed the friendship as it gave her the opportunity of going to the cinema or bowling. However she did live over an hours drive away.

Driving was an essential part of Angie’s life, especially now that she lived in a rural area. The transport links were few and far between but when Angie tried to drive she had no sense of direction, both in finding locations and getting home. Any journey involved planning routes on the computer beforehand and a number of times she found herself lost and had to ring her Dad to come and find her or guide her back. The introduction of accessible satellite navigation was the best invention ever for Angie as it hugely contributed to her independence, even though she found herself lost with this sometimes.

One may have thought that Angie’s difficulties of finding her way from place to place would have deterred her from fulfilling a long-held desire to travel
independently but it didn’t. Her German pen friend was spending time travelling and working in Australia and New Zealand and Angie decided to try this too. She made her way to Australia and met up with her friend for a short time before making her own way round for a number of months. She took agency work in care homes, which wasn’t without its difficulties: she was left with more responsibility than perhaps temporary staff should have been and it led to her sometimes forgetting essential tasks. However, she always acted responsibly and contacted the home if she remembered later. The social awkwardness was less apparent staying in hostels as often people were transient and it meant she didn’t have to remember their faces or facts about them. She did have some incidents that were due to this, such as agreeing to meet someone somewhere and not being able to find it, which led to her feeling guilty afterwards. Her employer allowing a sabbatical after so many years service made the trip abroad possible.

She was by now working in a social care setting with a very high caseload. She had tried general administration work but it didn’t suit her as she always planned a career working with people, helping with their injustices, just as she had with her brother Jack over the years. When she had begun her employment with the organisation she had found her manager supportive and provision was made for her to have a period of induction and a weekly session of home working. The home working allowed Angie to spread all of her paperwork out on the floor and organise it in a structured manner, as a strategy to ensure that she didn’t forget to do anything she was supposed to. However, as the department became under increasing pressure Angie didn’t have the time to engage with her usual coping strategies and it caused her stress. The stress made her memory worse and her manager appeared to becoming quite critical. Thus, coupled with the fact that she was managing an unreasonably large caseload of vulnerable people led to Angie looking for work elsewhere.

It made her question how much she would reveal her memory and prosopagnosia issues to in future, as when work becomes pressured she felt that it can be used as an excuse, rather than addressing the real issues in the workplace, as she does have a toolkit of coping strategies, which she goes to extraordinary lengths to put in to practice. She took another job linked to social care and advocacy with a charitable trust, this time being careful who she let know about her invisible disability.
Angie’s Mum encouraged her to make contact with The Encephalitis Society to see if they could be of any support to her as she was going through a period of feeling lonely. She followed this up only to find that most of the events were in the South of England, some distance away, but heard that there may be developments closer to home in the near future. She made herself known to them and was invited to come along to a weekend retreat. She was nervous about this, in light of the fact that social situations caused her anxiety, but with encouragement from her Mum she went along.

On the retreat, for the first time she met people with similar difficulties to herself. This was a huge relief to her because at last she had found people that understood exactly what she had been going through for so many years. She no longer felt alone; even though her parents had continued to be supportive and lived close by she couldn’t help but feel that the relationship had changed with her illness and that they didn’t really understand what it was like to experience the things that she did. But here on the retreat she found many people that did just that! It was the first time she had felt normal in a social situation since her illness. She bonded immediately with a number of people. One friend taught her not to take herself too seriously: she had experienced a different type of encephalitis and now mobilised in a wheelchair. Angie was inspired by her coping with far greater challenges than she was ever presented with. Another friend, Alison, had prosopagnosia similar to Angie and they were able to share how they managed. A difficulty was that they usually didn’t recognise each other on meeting, so they devised a way of doing this; the symbol for the charity was a jigsaw piece so they made matching necklaces with a jigsaw piece that they wore to overcome this. Alison even introduced her to a male friend she had met whilst in hospital. He also had a brain injury and Alison was sure that they would be a good match, which indeed Angie and him have become.

Angie looked back on the retreat as a real turning point in her life. At last she felt an answer to the “Who am I?” question that had been in her head for many years. She decided to take on the role of regional representative for the charity, which involved being a link person with people who contacted the charity in her local area and offering information and support. She also wrote a poem about the experience, which was published in the charity newsletter.
Angie now lives in a small rural village and is very much part of the local community but doesn't recognise her neighbours or other people who live in the village. Her fellow churchgoers are aware of this as her Mum is also friends with them and discloses this. She finds the community much more conducive to her daily life than the large urban town, where she worried about not recognising her peers from school when they stopped to talk to her. She finds the church friendly and welcoming and has taken on some roles of responsibility there. She takes part in activities in the village hall, such as keep fit and tap dancing and socialises with the women afterwards. Overall the difference between the large town and small village is that she feels a more equal member of the community here and less likely to be judged. It also means that she is close to her family and she can continue to help her brother. They have a routine of going to church together on Sundays then eating Sunday lunch together. Her boyfriend is currently considering moving to the area to be with her, but as he is unable to drive due to his acquired brain injury they will need to move from the village as the local transport network is extremely limited.

In her house she extensively utilises labeling as a tool to identify where familiar objects are, such as her clothes and kitchen items. Her bedside calendar is part of a regimen of turning it over last thing at night for purposes of orientation with date and time. She relies on a birthday book and large wall calendar to ensure that she can plan what is happening on what day. She has experimented with a ‘sense-cam’ given to her by the Encephalitis Society, which keeps a visual record of events that she can load to her laptop. This is partially successful in that she would benefit from being able to record audio information to remember what she had been doing at the time of the visual record as her verbal memory is better than her visual one. Video recording in her daily interactions is limited though, for example due to retaining peoples’ privacy and she does not wish to highlight her usually invisible disability.

One strategy she employs is the choice she has made of partial disclosure of her disability in the workplace. Only some of her colleagues know of her disability. To ensure she has a method of avoiding social awkwardness she watches the television news on a daily basis, which arms her with ready conversation so she doesn’t have to remember facts about work colleagues, to make conversation with them. She engages with prolific indexing and diary writing, or she has no memory of what happens from day to day. One manager
took away the opportunity for a weekly session of home working, which posed a problem to Angie, working in a busy open plan office and no longer having a weekly catch-up to spread out her notes and organise in a quiet environment. It means that she brings an amount of her work home with her to sort outside of office hours, especially now she has gained a managerial role. The work role is not that of an occupational therapist as she had always hoped, but she has followed a similar career path and the work covers similar issues.

Reading self-help literature about discarding 'negative chatter' has been very helpful to Angie over the years. She makes the link between the positive thinking in the books to her understanding of religion and sees the connection between them as a way to interpret life. She is aware that through the restriction in opportunities to make social contacts over the years, her friends are either much older than her or have disabilities and whilst valuing these friends she is aware of an absence too. Reflecting back on what she has gained from her experiences she thinks that perhaps her life has made her stronger and more open to different experiences than she may otherwise have been had she not experienced acquired brain injury. The amount of time and effort required to implement her toolkit of coping strategies is considerable but she continues and is always open to learning new ones. She is still ambitious for the future.
Appendix P

Example of analysis of narrative – Participant 3

Analysis of narrative - Participant 3 – Angie – A woman with daily life dominated by facial blindness

Positional aspects of Angie’s narrative interview

I had first met Angie at an event when I did a presentation on recruiting to my research and she had expressed an interest in taking part. I was therefore surprised when she checked who I was when I called at her home at the pre-arranged time. This was an example of her hidden disability of prosopagnosia, (face blindness), which is at the centre of her coping with daily living.

I was worried that she may not be able to give her life story, with having little memory before age 18. However, I was impressed by the extent of her coping strategies, for example the diaries she had maintained over the years, as a written memory of her life. She talked about not being able to fulfill her dream of being an occupational therapist and not being allowed to implement her coping techniques during practice placement as a student. I empathised with this situation as I see this happen with my own students and feel helpless at times and maybe I should rethink the adjustments we make for students. I felt that I wanted to reassure her that the type of role she currently held was indeed similar to many that occupational therapy graduates apply for now. It struck me that she would make an excellent occupational therapist when she described her life and the experience of implementing so many coping techniques.

Overall, I was struck by how she carried a sadness about the small social circle she had, yet in actual fact it is probably as big as the average person’s. Perhaps this was due to many of her friends also having disabilities and perhaps this was an issue of feeling socially excluded from many non-disabled groups i.e. social exclusion as opposed to social isolation.

Analysis of Angie’s Narrative

Angie is in her late thirties and lives on her own in a small rural village. Her family live nearby. She grew up in an urban environment some distance away.
from the area where she now lives. When Angie was seventeen she became ill following a holiday in Spain. She fell into a coma and was eventually diagnosed with encephalitis, resulting in an acquired brain injury. The symptoms of the injury include propopagnosia, (face blindness), sequencing problems and memory loss, as well as changes to her sense of taste (Headway, 2016b). She holds little or no recall of her childhood. Her career aspirations to be an occupational therapist were thwarted but she did complete a degree. She has always worked in the health and social care sector, currently in a management position, reflecting an habituation with a desire to help people through work (Kielfhofner, 2008). She is independent in most aspects of her daily life and draws on numerous coping strategies to enable this. She volunteers for a brain injury charity, offering support and guidance for people who have received similar diagnoses, indicating altruistic behaviour (Babula, 2013).

Angie’s narrative tone appears to be pessimistic as opposed to optimistic. This may be due to the impact of a biographical disruption during her adolescence, when her aspirations were brought to an abrupt end (McAdams, 1993). She grew up with supportive parents and describes her mother as very practical and her father as impatient. She was close to her brother who was born with cerebral palsy. Her mother worked in a special school and she always wanted to be like her mother, which led her to look for a career in a helping profession. This suggests identity through kinship (Lawler, 2014). She holds little recall of childhood events or her life prior to the brain injury at age seventeen, just prior to her eighteenth birthday. Having seen her brother cope with his disability inspired her to find ways to cope with her own.

She describes her life as being, ‘a little boring’, as she is not able to be spontaneous: going to new places involves careful planning, such as how to find her way there and how to recognise people in social situations, even familiar people (Headway, 2016b). She uses poetry as a release of emotions (Edwards, 1990) and has had some of her poetry published by the charity with which she is involved. She engages in a multiple daily practical coping strategies.

Angie's narrative is stable up to age eighteen from what she is told, but she recalls little of it, ‘it's been sort of been wiped a bit or it's vague’ (1/26-28) (Gergen & Gergen, 1986). She had grown up with a disabled brother, who at times had challenging behaviour in the family environment. This influenced how
she saw disability: inspired by what someone can achieve in spite of being at a disadvantage in life, thus attributing a positive social representation of people with disabilities (Moscovici, 2000). ‘He was er, in the Special Olympics, you know swimming events, basketball events, and competitions and things’ (2/10-16). She also wanted to be like her mother and her mother worked with people with special needs, again emphasising identity through kinship (Lawler, 2014).

She describes a normal teenage life, socialising with friends and had her first independent holiday with a friend at 17, which is when she became ill.

A major regression then followed. Angie objectifies her illness of encephalitis as something that strikes ‘and that’s when encephalitis struck’ (1/36), suggesting a catastrophic reaction to her neurotrauma (Medved & Brockmeier, 2008). This signifies the acute start to her biographical disruption and the huge impact it has had on her life (Charmaz, 1999). In conversation she laughs at the irony of waking up from the coma on her first day of adulthood, her eighteenth birthday (1/44).

Angie uses the word, ‘Bye’ to describe her hospital discharge and to suggest that she was no longer under any health service care because she was physically well, yet she was a long way from being able to re-engage with her life (1/56), suggesting a medical model of intervention predominated, that took no account of the emotional or psychological difficulties she was also facing, (Bradby, 2012). This led to frustration at home and a number of emotional outbursts, which she didn’t feel she could control, even though she felt guilty about them afterwards (Headway, 2016b). It is common for ABI to have a significant impact on the family environment for similar reasons. This is the first time that her identity was challenged as her mother told her that she different (Nochi, 1998b), ‘I know it’s not you’, (2/2074). Her relationship with her parents deteriorated and although they remained close her mother questioned who she had become. Angie felt like the same person inside and still felt like her pre-injury self. She began to ask herself the question, ‘Well who am I?’ (1/323). As a result she found her parents a great help whilst at the same time they did not understand what she was going through.

Her memory and recognition difficulties from age eighteen had a huge impact on her social interactions with her peers (Headway, 2016b), as she was no longer able to recognise them and recall information about them that is typically
incorporated into everyday conversation, ‘Cos conversations were very difficult’, (1/240). She could no longer socialise in the evening due to fatigue (Headway, 2016b) and developed a dislike of alcohol due to her taste being affected, which made identifying with her peer group difficult and heightened the social difference (Tajfel, 1978). This resulted in her becoming increasingly frustrated with life, ‘So er, I got very frustrated with, you know, not sort of knowing who anybody was, not being able to er, sort of have much of a social life at that point’, (2/148-150). Being at the adolescent stage of psychosocial development, socialising and identifying with her peer group would have been very important (Erikson, 1959). This caused her to lack confidence in everyday interactions and she continued to question her own identity (Nochi, 1998b). It was also the time her closest friend died and culminated in a period of having panic attacks, nightmares and depression (1/88-90), demonstrating the emotional impact of biographical disruption (Charmaz, 1999). The emotional impact led to seeking medical help, which was the first time a specific referral to diagnose the cognitive deficits of ABI was accessed. The diagnosis of prosopagnosia (1/92), was made by a psychologist as well as additional cognitive issues such involving memory and sequencing.

As sequencing was now difficult, due to executive functioning difficulties, she had to write instructions of how to carry out tasks (Headway, 2016b). She had taken her A Levels before her illness and didn’t achieve the grades to begin her occupational therapy programme at university. She excuses her self for this by way of explaining that her best friend was terminally ill and she spent time with her and her boyfriend i.e. not achieving a balance between study and social life, ‘my mind wasn’t really on it’ (1/70), being careful to present herself as intelligent but distracted (Moscovici, 2000). She was given special learning support at college, now that she had an ABI and eventually began her university course. University life was difficult for Angie as she was discontinued from her chosen vocational programme, she thinks because she wasn’t given enough opportunity to put her coping strategies in to practice, such as additional note taking, ‘So they failed me on the placement side. They said the academic side I was fine’, (1/136). Overall the expectation of the university was higher than Angie could demonstrate, without additional support, moving her beyond her zone of proximal engagement (Vygotsky, 1978). This was during a time when there was less awareness of disability rights to support students with special needs. She describes her lack of challenge to the university’s decision down to not being
She also struggled to make friends there, due to most social activities for her age group involving alcohol, which she could no longer drink due to issues with gustatory perception. This may be due to lesions in the taste pathway (Headway, 2016b). She was ‘heartbroken’ at this loss of career and future life script, which she had held since being a child (1/146) (Charmaz, 1999). At the time she felt it was ‘the end of the world’ (2/381) suggesting a romanticised view of her life not turning out as she had hoped (Frye, 1957: Cashdan, 1999).

At this point she returned to poetry as a means of expression of emotions (Edwards, 1990). This was something she had come across as a coping strategy with a fellow patient when she spent time in hospital following the ABI, ‘that really helped me to understand what she was going through and what was happening to her’ (2/1886). With respect to academic ability, a doctor told her that she wasn’t capable of achieving a degree, which was an unjustified judgment and she did in fact go on and achieve a non-vocational degree, ‘He actually told me he didn’t think I was going to be capable of getting a degree anyway’, (2/433). This suggests a medical model of care where the complexity of individual perspectives are not considered (Bradby, 2012). However, she describes herself as having ‘fighting spirit’, inspired by her brother’s achievements despite his disability.

After university, a period of unemployment followed, which she used to gain work experience by volunteering. She found that she didn’t enjoy administrative work whilst volunteering and switched to gain experience that involved helping people, as this was what she had wanted to do if she had completed her occupational therapy degree, ‘I asked to change and go on to something a bit more people centred (1/170). This reflects an habituation of helping other people (Kielhofner, 2008). Employment opportunities since have been taken up around social care, pursuing her desire to be involved with a helping profession. There is a dissonance between wanting to have work that provides intellectual
challenge and work that she manages to cope with, ‘And it didn’t really stretch me very far’, (1/196). Certain aspects of roles required additional time to cope, due to her memory and sequencing issues (Headway, 2016b). This has caused relationship issues in the workplace. She describes past workplace environments as ‘quite a challenge’ (2/1005), due to pressure from managers. Stress caused when she felt she was getting behind only served to amplify the issues, as it would increase her cognitive difficulties (Headway, 2016b).

She moved with her family to a small rural community a few hundred miles away from where she grew up. Angie made several attempts to join social groups, but found it difficult to meet people whom she felt had the same social needs. This would indicate issues with managing social identity (Lawler, 2014). Social situations could become awkward, as she could never remember people or details about them to make conversation. She was unable to be spontaneous. Additionally every social event was like walking into a room full of strangers. She felt that the symptoms led to her being at a social disadvantage and to not gaining friendships and she felt socially isolated (Eriksson, Kottorp, Berg & Tham, 2009). Whilst she was able to go places with her family social opportunities with her peer group evaded her, at a stage of psychosocial development when individuals usually become independent of parents (Erikson, 1959). Over the years health professionals suggested strategies to overcome the propopasnogia in social situations, such as making notes about people when they tell her things. But this was not practical as it drew attention to her and singled her out as different, again causing social awkwardness, ‘And er, it’s hard to sort of use those strategies without feeling totally stupid’ (2/294-296) suggesting further issues with social identity if she reveals her disability in public (Olney & Kim, 2001).

She took a job with an advocacy organisation, which she loved as it involved making a difference to people’s lives. Eventually the funding ceased and she was looking for work again. More social care work followed and one employer offered the opportunity to take a sabbatical. She capitalised on this and moved to Australia and New Zealand for six months. This gave her the opportunity to meet new people on a daily basis, which eradicated the need to remember details in social interactions and she quickly gained self-confidence, ‘you were meeting people on a daily basis so they didn’t know I hadn’t got a clue who anybody was’ (2/1424).
Over the years Angie has found books written by inspirational people who have overcome adversity helpful in coping with her own life, indicating her engagement with positive psychology (Seligman & Csikszentmihalyi, 2000). She describes reading one of these books as ‘Cos there was lots of things in there that just made complete sense’ (2/2735), drawing on positive psychology as a coping mechanism. She utilises positive thinking and affirmations to overcome what she calls ‘negative chatter’.

She utilises a vast array of coping techniques to aid memory and recognition. She has drawn up multiple lists to aid sequencing everyday activities, such as using the washing machine. She keeps a daily diary so as she can recall details about her life (when other people may draw on their memory), ‘Tomorrow I couldn’t necessarily remember what I’ve done today’ (2/671-673). She watches the news on a daily basis to make ready conversation with people at work to cover up for not remembering details about them personally. A ‘sat nav’ is invaluable to her in order to make her way around in the car or on foot. Calendars help to orientate her to days of the week and up and coming events, none of which she would remember if not recorded. She arranges to wear similar jewelry to a friend so as they can recognise each other due to both of them having prosopagnosia. She still sometimes writes poetry to express her emotions (Edwards, 1990). She has tried using a machine called a ‘sense cam’ that visually records what she is doing and she plays it back afterwards for recall. Cupboards in her house are labeled as to contents for ease of finding things.

She describes being introduced to The Encephalitis Society as a turning point in her life: she met people with similar issues who understood what it must be like with a similar illness experience, ‘And, and that was the first time since having the illness that I actually thought, ah, that’s what it’s all about. So I’m not, not abnormal. Other people have got it’ (1/319-321) (Charmaz, 1999). She became inspired by some of the friends she made, demonstrating the social capital support role played by connecting with similar people (Bourdieu, 1986). This was the first time in years that she felt no social awkwardness, due peoples’ similar experience and understanding. This can be explained in relation to social identity and being accepted, ‘and that was the first sort of social situation where I felt normal’ (2/1822) (Tajfel, 1978). Also for the first time she met another
person with the symptom of prosopagnosia and she was able to connect with them and become good friends. They also encouraged her to use humour as a way of coping too. As a result she began to volunteer for the charity.

From this point onwards the narrative was able to move forward and progress (Gergen & Gergen, 1986) and Angie was able to stop expressing abnormal anger and being self-deprecatory. She met people who she considered to be far worse off than herself, yet had a positive attitude and this inspired her (Seligman & Csikszentmihalyi, 2000) and she possibly utilised comparison processes to arrive at this point, ‘I don’t have to have people do things for me so it made me feel, you know put it into perspective really’ (2/2148-2150) (Festinger, 1954).

However, today the narrative appears stable, with no progression to her former level, as there are still many daily issues to deal with (Gergen & Gergen, 1986). She has an intense daily routine of managing her own coping strategies and managing her disability at work, both to cope with work demands and in terms of who she reveals her invisible disability to, so as not to experience prejudice, ‘Cos when people focus on it I think it makes it worse’ (2/1182) (Olney & Kim, 2001).

She has a routine of full time work and engagement in her coping strategies of diary writing etc. She eats with her parents once a week and attends church with them. She continues with her trait of helping by taking her disabled brother to a swimming group, to help with his self-esteem. It has made a significant positive difference in her life by having a partner, contributing to social capital (Bourdieu, 1986). From an environmental point of view Angie finds it easier living in a small village with a small population, rather than the large town that she grew up in as she found it awkward not recognising people she had gone to school with. However, her partner is going to move to live with her but due to his ABI he is unable to drive and the rural setting has few transport links (Leonard Cheshire Organisation, 2010). The rural setting is friendly and sociable and she doesn’t feel judged by those around her, especially at church. She finds a sense of belonging here, which she values.

There is a clear occupational persistence or habituation in Angie’s narrative around helping others. She made this decision whilst growing up, influenced by her mother having this career-type and also was familiar with people requiring
help due to her brother having a disability (Kielhofner, 2008). Unable to be an occupational therapist, she uses many problem-solving techniques to cope with her own life, much like an occupational therapist may have advised her to engage with. This is also reflected in her series of employment roles over the years and the volunteering activity she does for the brain injury charity.
Appendix Q

Verification of Angie’s story

Claire <C.Brewis@tees.ac.uk>  Subject: Re: RE: Brain injury research follow up

Hi Claire

Thanks for the reminder and I must apologise as I had read what you’d previously sent and intended to reply and then other things took over and I forgot!

I think your case story was a very accurate portrayal of what happened to me and how it felt and was quite surprised at how much you had actually taken on board from our 2 meetings.

I am not fully clear what role the photographs played in the research but think you have gained a great understanding of my experiences through using them to discuss my case story with you. I would be keen to hear what conclusions you come to when you complete your project and how you think this will help practitioners or survivors in future.

Good luck with the next phase of your research and I look forward to hearing how it goes.

Regards

----Original message----  From : C.Brewis@tees.ac.uk  Date : 12/10/2015 - 14:25 (BST)  To : ne.choc@btinternet.com  Subject : RE: Brain injury research follow up

Hello,

I didn’t hear from you after sending the case story I’d written. I thought I’d give you a prompt in case you had forgotten. I’ve attached the case story again, where I gave you the pseudonym of Angie.

Best wishes,

Claire

Claire Brewis, Principal Lecturer / Subject Leader Occupational Therapy, Teesside University, Middlesbrough, TS1 3BA | E: c.brewis@tees.ac.uk | 0044 (0) 1642 384130 | @cbrewistees
Appendix R

The Remaining Narrative Analyses (not contained within the main thesis or example offered above):

Participants 1;2;5;6;7;8;10;11;12
Appendix R: Narrative Analysis

Participant 1 – Rachel's story

Rachel is in her early 50s and married to Sam. She has a teenage son, Tobias and they live in a rural town in a predominantly agricultural area. Sam had a brain injury as a result of having a brain tumour removed, approximately nine years ago.

Rachel moved to the rural town when she was a young child, having previously lived in a city over a hundred miles away. She was the youngest of three siblings, with her brother and sister significantly older than her, which made her question if her birth had been planned. Her childhood was normal and proper in a traditional British family of the 1960s, where her father went to work in a managerial job at a local factory and her mother adopted the role of homemaker. They involved themselves in the local community with activities such as attending church on Sundays and her mother was a member of the local Women’s Institute. The family regularly returned to the city to visit her grandparents. She knew that her maternal grandmother lived in unusual circumstances that she didn’t make sense of at the time, with being a child. She disliked visiting, as her grandmother was always in bed, clearly ill, with a repulsive odour in the house. Her parents encouraged her to maintain an affectionate relationship with her grandmother, which was difficult for a child not understanding why her grandmother didn’t speak to her and behaved strangely.

From about the age of eleven years of age she became aware of her own mother’s failing health. Rachel began to express concern to her mother but that concern was not acknowledged. The family was unable to obtain a satisfactory diagnosis from the local general practitioner but Rachel’s older sister was persistent in rejecting the explanation of her mother’s decline in health being due to the menopause: being nine years older than Rachel she was aware that her grandmother had an hereditary degenerative neurological condition and it was highly probable that her mother was developing similar symptoms. Her mother’s health continued to deteriorate and she withdrew from the local community such as church and the Women’s Institute.
Rachel's sister had married and left the family home and as her mother became more dependent the caring role fell to Rachel, from her early teenage years. Her relationship with her father significantly deteriorated, possibly due to the stress he was experiencing with his wife’s declining independence and maintaining his role as worker. Rachel experienced continued verbal, emotional and physical abuse in the home for several years. It was an environment with a high degree of emotional charge. She was controlled by her father and made to feel guilty if she didn’t fulfill the caring duties towards her mother. Potential stigma surrounded the family environment and her father forbade her to speak out about the difficult situation, as it would bring shame on the family. She was restricted in her socialising with friends and her attainment at school was limited due to priorities being within the home and the enforced caring role. The love for her mother was the factor that kept her at home, despite the relationship with her father breaking down. Rachel, influenced by her experience of being a carer, had career aspirations to become a nurse or midwife and was accepted to train in a city about 90 miles away. She was forced to withdraw her application by her father who said he would not allow her to see her mother ever again if she took up the place and moved away. She obeyed her father, as she could not bear the thought of being estranged from her mother.

During the difficult years Rachel was introduced to a nurse, Paul, employed by a charity supporting people and families in relation to her mother’s degenerative condition. This man had a high national profile with the charity and she describes this man as her ‘guardian angel’ and held him in extremely high regard. She embraced the opportunities to become an advocate for families with the condition and took part in educational seminars, offering a young carer’s perspective on the illness experience. This gave her the opportunity to become well informed about ill health and health service availability, as well as being given the public stage with medical practitioners and researchers. It gave her an interest in fundraising and promoting awareness of the condition in the area where she lived and nearby, which is something that she continues today. One Easter she was cast in a television documentary with celebrities who had had difficult experiences, each representing an aspect of the Easter story and Rachel’s story was portrayed as, ‘The cross to bear’, which she took pride in. Paul also helped the family access the available healthcare for her mother at the time. Although a relief in part, this was quite frightening for Rachel as it involved taking her mother to the large psychiatric asylum and entering the locked ward.
with some severely mentally ill people, which was quite alien to anything she considered her family to be part of. Above all, Paul seemed to understand what she and her sister were coping with in the family situation.

Rachel always acknowledged spirituality in her life, in terms of events being in the hands of fate and drew on this as a means of acceptance of circumstances. She also felt that some of her family had a degree of psychic ability in terms of being able to see what the future may hold. She held a belief that, ‘bad things happen for a purpose’ and eventually there will be relief and optimism.

Her mother passed away when she was 26 and this relieved her of the role within the family home and she went to work in a large local factory. This gave her the opportunity to meet many more people and is where she met her husband Sam. They had a wide circle of friends and enjoyed activities such as pub quiz nights, playing darts and pool and socialising. Sam introduced her to a new interest of attending live music events and she developed a keen interest in rock music, finding it a valuable form of expression of the difficult times she had encountered in the past. Rachel and Sam enjoyed travel and holidays overseas, which became an important feature of their lives in the years to come.

Sam was a man who had also had a turbulent home life and in that they had a shared understanding of difficult family environments and she viewed this as a strength of their relationship. Their trust and understanding developed over the early years of the marriage and they came to learn that Rachel was a carrier of the gene that led to the disability and early deaths in her maternal lineage. This placed a future responsibility of caring for Rachel on Sam, in the earlier years of the marriage.

Rachel and Sam wanted to have a child but Rachel was cognisant of not wanting to pass on the hereditary condition that she was a carrier of, to a son or daughter. To overcome this difficulty they opted for in vitro fertilisation with a donor egg. The process was long and emotionally difficult but they did have a long awaited son, Tobias. Rachel gave up her work at the factory and became a full time mother, occupying her days with childcare and homemaking, which she enjoyed, despite the loss of the social contact at the factory.
The factory eventually closed and Sam took up work with a hardware company in the rural town where they lived. This involved him being away from home at times, driving for the company and it was on one of these occasions, that the incident occurred which Rachel recalls as the beginning of the nightmare. She received a phone call informing her that Sam was seriously ill in a city hospital about 70 miles from home. In retrospect Rachel acknowledges that they were very fortunate that this happened whilst Sam was away from home and so close to specialist services, as their rural town was remote from intensive care services and he may not have survived a time delay in reaching hospital. She made hasty plans to be with her husband, leaving Tobias, who was seven at the time and their pet dog, in the care of neighbours as the school term was still ongoing. A few days later the neighbours kindly delivered Tobias to the hospital to be with his parents. It was difficult for the family living in hospital facilities whilst Sam underwent tests to try to find out what was the cause of his sudden illness, but they wanted to be there to support Sam. Sam was diagnosed with a brain tumour and underwent lengthy surgery. Rachel’s past expectations of healthcare, with her mother and the support in that previous situation offered by Paul, allowed her to confront the abruptness of medical staff in this new and unexpected situation and she asked for clearer explanations and more respect, which she feels was acknowledged in part. Tobias also stood his ground with nursing staff, who questioned his mother in allowing a young boy to see his father in a distressed state and Rachel was proud of her son’s caring response to this.

The subsequent brain injury, from the removal of the tumour, saw the onset of a prolonged period of marital turbulence. Rachel had a fantasy that this life-changing event would bring an emotional enhancement to the marriage and a spiritual connection, in that Sam had been close to death and that life henceforth would have a new meaning for him. Instead Sam’s behaviour began to remind her of what it was like living with her father again, with emotional barriers present and having to cope with stereotyped male behaviour patterns. His mood was unpredictable but predominantly very bad. Rachel predicted psychological difficulties and enquired about this from the outset, but Sam denied that his behaviour had any psychological origin and was angry with Rachel for suggesting this. He became increasingly self-centred. She felt that Sam rejected her and Tobias and he seemed to be very angry and was requesting a divorce, which she failed to understand as she had merely tried to be supportive and
caring at all times. Family outings in public spaces caused embarrassment due to explosions of temper on Sam’s part. Sometimes she didn’t recognise her husband in the actions that he did. There was behaviour such as staying out at night without notice or explanation, ongoing friction with her sister and family and it began to take its toll on Tobias.

As Rachel had seen the benefit of involving services in difficult family situations with her own mother, she was happy to seek help through the social services, even though it ran risks of alienating her husband even further, but she recognised that her and Tobias needed help. She didn’t want Tobias to be harmed by the circumstances at home, as she herself had experienced in her own family life. This intervention brought rewards, as support was put in place for Tobias in the form of counseling, which developed into longer-term support. It was also at this point, when Rachel indicated to Sam that if there were no change in his behaviour, that he may loose his son. Thus, Sam agreed to engage in counseling for himself. This was against the perceived view of Sam that it would be of no help to the family situation. The engagement in counseling had immediate positive effect.

The turbulent period lasted for three years and although emotionally difficult for Rachel she was extremely pleased that she persevered in the marriage. She came through the difficult times seeing herself as someone who is tolerant, strong and resilient and her husband as calmer, friendlier and more open to negotiate on matters. She feels a sense of justice in looking back over the difficult times to the state of resolution that is now apparent in the marriage; she had shown compassion and care with little reward in the past but latterly this appears to have been acknowledged. This care and compassion has been an ongoing trait displayed by Rachel over the course of her life, from career aspirations, her role as carer for her mother and now in her marriage and the approach to living with a partner with acquired brain injury. Many of Sam and Rachel’s friends' marriages have broken down in less challenging circumstances and Rachel puts the perseverance of her marriage down to her resilience and past experience of difficult times, both as a young person and experiencing the shared emotional strain of waiting a long time for a child in the marriage. Although this past experience of dealing with anger and emotional rejection has now passed Rachel is still very anxious that it may return at some point in the future.
The role of carer brings with it a multitude of anxieties for Rachel and she often copes with this by seeking relief through removing herself from the family home and sourcing friendship in female company. She supports her main friend through her relationships and stressful life events and in turn receives support from her friend. Seeing her friend's son play reminds her of happier times in her own life when Tobias was small as her own mothering role is required less as Tobias matures. Sam finds it difficult to understand why Rachel feels the need to escape from the house to her friend's house or to the local coffee shop to read and relax. He finds pleasure being in the family home and sitting quietly with sedentary pursuits. Rachel, however, feels discomfort in the home and feels the need to escape. Spending time away from Sam makes her feel guilty but it doesn’t stop the urge to do it and she continues. She also looks to the future and hopes one day to be able to leave this house behind and move to somewhere like Italy to retire and take enjoyment in more beautiful surroundings. Her dream has been stalled for the time being because of the uncertainties presented by Sam’s changing health status.

Living in a rural town is limiting for Rachel as there is little access to culture and leisure pursuits that can be restorative and help maintain health and well-being. As small towns have seen a decline in shopping and leisure outlets in poorer economic times she and Sam have to travel further afield to satisfy this. Public transport is expensive from their rural town. Sam is no longer able to drive due to his acquired brain injury, so Rachel has assumed this key role. This is not without criticism from Sam, who sees himself as the having more skills in driving but has had to relinquish the role of driver himself. The future is uncertain for Rachel on terms of how long she will be able to maintain this role due to her own health limitations.

Both Rachel and Sam have disabilities that are not visually apparent, as both have a neurological origin and currently little physical impairment. This can cause upset if professionals don’t understand the complexity of this and at times she has found people uninformed and ignorant of how they struggle. This has happened in terms of having the validity of benefit claims acknowledged, despite repeatedly detailing this in lengthy written applications. Having a health professional who is well informed has been particularly useful to support her claim when questioned.
A significant amount of their routine is taken up with hospital appointments. Often it involves seeing a number of different healthcare professionals on one day. At the moment Rachel is able to drive them both to the hospitals. She feels a strong need to connect with others in similar situations but doesn’t find those opportunities on hospital visits; waiting rooms don’t appear conducive to striking up conversation and even if they did it would be rare to find another couple where both partners had significant health concerns. Instead she has looked to charities to find that connection but the depth of engagement she found with the charity in her earlier years isn’t forthcoming. Her and Sam try to engage in the fundraising and promotion but few others reciprocate. She is appreciative of the charity organiser but the charity lacks a paid worker who can develop the work of the organisation and provide the kind of opportunities she is looking for. As Rachel has taken the role of helping others through a charity in the past she feels she has something to offer others who come to the charity for help but doesn’t get the chance to talk to them to fulfill this role.

A few years ago Rachel undertook a volunteer role and one of her dogs became a PAT dog. They visited nursing homes and offered company to elderly people and Rachel found it fun and rewarding, as well as the status from this official role that not everyone (or every dog), is accepted to do. For Rachel it filled the gap of no longer being part of the charity with Paul in the past. Eventually she felt guilty at spending time with people away from home, in that she should perhaps be at home with Sam who was ill too. She reluctantly gave up the volunteer role because of this.

Rachel and Sam have shared activities such as reading and listening to music at home and attending live events. She has always had a passion for music and in the past found solace in lyrics during difficult times of her life. She has one musician she particularly identifies with through the music and had his face tattooed on her arm as a marker of this strong identifier. She cherishes a moment when she got to meet him and talk to him face to face backstage at a live performance. Together Rachel and Sam visit the cinema and take trips in the car to coffee shops and cafes. Occasionally they may meet friends at the pub but Sam is less keen to do this as much as previously. Rachel would like him to do this more but doesn’t want to put pressure on him to do something he is reluctant to do. Usually it is activities with just the two of them. They walk the
dogs together or take turns with the daily dog walking routine. Rachel is especially fond of bargain hunting at car boot fairs or charity shops and in the past she has enjoyed being a vendor at car boot fairs to raise money for charity.

Due to Sam’s health status activities are limited somewhat now. Fatigue is a key factor that requires him to rest for long periods. His work hours have subsequently reduced, bringing with it reduced income to the family home. Future plans of moving abroad have been halted which she finds frustrating. A part-time degree course he was doing has been halted too and Rachel used to enjoy this as she accompanied him on associated outings.

The future still carries many uncertainties, as Sam’s tumour has returned and they know that his life expectancy is greatly reduced to between three and nine years. This presents sadness and guilt in Rachel’s mind in that Tobias has potentially both parents surrounded by illness. They adopt an honest and open approach with Tobias, being realistic about the future and what he may face, at the same time ensuring that he is supported with counseling from outside of the home. She also acknowledges a role reversal in the marriage by way of previously it was considered that Sam would be carer for Rachel in the future, should her symptoms become debilitating. For this reason she adopts an approach of living in the present to counteract the role strain and anxiety of the future.

Spirituality plays an important part in Rachel’s life. She can find comfort sitting quietly in church. She tries to understand why life has turned out as it has for her but has no answer to this question as yet. Whereas previously Sam didn’t acknowledge this part to life he now attends the Buddhist Centre with her occasionally and she is learning how to be happy by engaging with this way of thinking. Rachel is someone who has always tried to be caring and kind, but has not received this in return from those around her or events that have happened to her. A number of people dear to her are no longer in her life and she questions why this has happened to her repeatedly with people. Some have died and others have become estranged, such as her sister, father and friends. She feels a ‘greater presence’ who has seen her in this caring role throughout her life and perhaps who understands what she has always tried to do and that God has a plan for her.
Appendix R: Narrative Analysis

Participant 2 – Sam’s story

Sam was born into a coal mining family in the early 1960s. His family consisted of his mother, father and much older brother. This was a community where most of the men went to work in the local pit. Money was tight and times were hard. When he was four his mother and father divorced and unusually for the time, his father won custody of Sam and his brother and endeavoured to bring them up alone. His father struggled and had a difficult time with the situation: he was an underground worker, had to cycle to the pit a number of miles away, work long shifts and then return home to see to his boys each day. Sam idolised his father, growing up in this male-only environment. Sam hoped he meant a lot to his father in return. He had no contact with his mother during his formative years.

Every day he walked home from the village school by the same route. One particular day, when he was about five years old, his friend offered him a dare: this was to walk home along the cemetery wall. He took his friend up on the dare, going all the way along the wall. This also involved taking a different route home from the usual one. He ran to the top of the hill to meet his father, who picked him up and gave him a lift home on his bike. When he and his father arrived home that day they found the house emptied, apart from his father’s old chair, a few plates and knives and forks. The rest of the household belongings had been removed by his mother, earlier in the day, even down to the carpets on the floor, with a plan to also take Sam on his way home from school. What he hadn’t realised that afternoon, was the coincidence that his mother had been lying in wait for him on his usual route to try to take him away to live with her, when it was the one day he walked home by a different path! His father simply got on with the situation. He climbed into the loft to bring down an old Bakelite television, set it up, gathered Sam up on his knee and sat down in his old chair to watch the television together. This only served to strengthen the bond between father and son. He saw other boys whose fathers seemed too busy to be a father to their sons, which was never the case for him. Life wasn’t easy and they had to do without many things but Sam always knew that his father did everything he possibly could for him. He was taught from an early age that if he wanted his pocket money he had to earn it and he would do whatever chore he could to this end: chopping sticks for the fire or cleaning shoes and even
shoveling coal into bunkers for neighbours in the street. His father had been a soldier in World War II for six years and the house was full of stories from the war, which Sam thrived on.

Sam frequently found himself alone as a boy. This led Sam to become familiar with entertaining himself in a solitary environment. He developed a love of model making and reading. He enjoyed films and books about cowboys and Indians and always used to side with the Indians as the ‘good guys’, puzzled as to why they were cheated yet not portrayed this way. When his father was at home they would make a table out of an old crate on which to play cards. His father was very protective of him and if the older boys in the street wanted to play football in their garden he would only allow Sam’s older brother to play if Sam was allowed to as well.

Sam didn’t enjoy going to school but he did enjoy some of his taught subjects. He found a real pleasure in history and unusually for a boy he enjoyed sewing. It was clear to anyone in his village that the only way to avoid following your father into work in the pit was to gain good qualifications or join the forces. Only two children from the village school were allowed to move up to the local grammar school and although bright, Sam wasn’t selected. He would have loved to have an opportunity to go to university but he was sent to a secondary modern school, where he eventually lost his way academically. This was in part due to his father’s deteriorating health. When he was twelve years old his father developed cancer and spent a lot of time in hospital some miles away. Every night when Sam came home from school he caught the bus to town to visit his father. With his father being the main element of stability in Sam’s life this became the priority over school-work and attending school. When he was fifteen, his father died. This was the man who was at the centre of Sam’s universe and now he was gone. His father had nothing to leave him due to their circumstances, except the legacy of being loved and cared for, under very difficult circumstances.

He moved in with his brother, who was by now married and applied to join the Merchant Navy. Two of his friends applied too. All three went along for the interview. One boy foolishly said that he wanted to join up as a way of avoiding going down the pit, which was true for all of them but not a wise statement to make at interview. Sam was accepted, subject to a clean bill of health, as was
the third boy. However, Sam had developed a nasal problem that required a minor operation. Surgery didn’t resolve the matter and he never made it to the Navy. The one boy who did join up did not see Navy service for long; a few years later he was asked to leave due to an alcohol problem and being drunk on duty. Sam looked back on this as a wasted opportunity, having not had the chance to become a sailor himself.

With no job or real home he decided to look for his estranged mother and ended up moving in with her for some time. This was not successful. He took a job in a seaside bingo hall, which he enjoyed, but didn’t have a good relationship with his mother. It was an emotionally difficult time for him, now that his father was gone and his relationship with his mother weak. He wasn’t thinking clearly and it led him to marry young and begin a family, probably before he was ready. The marriage failed. He made the move away, to work in a factory in a village some miles away. At this point he still regretted not having the opportunity to go to university. He thought about studying for a degree part time with The Open University, but the fees seemed prohibitive. He’d become used to earning a wage and taking this home and the opportunity to study seemed to be passing him by.

Whilst working at the factory he met Rachel and married her. This was a successful decision. They made a home in the village and eventually they had a baby boy, Tobias. As the years passed the factory closed and he tried his hand at various jobs. He set up a business with a friend erecting gravestones, became a taxi driver for a while but eventually settled into a job in the local paint shop. Sam worked hard against the backdrop of the work ethic he developed as a child. He worked his way to becoming the shop manager and felt he couldn’t develop any further in that this line of work did not offer a career. He questioned the owner over his sales bonus scheme. Sam’s principles involved not making a sale to someone who would regret their purchase in the long term, yet the bonus system didn’t seem to take this into account. Sam liked to think that if he gave sound advice rather than just a sale, the customer would respect him more and be increasingly likely to use the shop again.

The firm had shops in a number of neighbouring towns and cities and one day the owner required some help in a nearby city where the shop had staffing problems. Sam volunteered to go over for the week to help out; it was close to
the village in which he grew up and it held certain nostalgia for him. In the lead up to this trip, he hadn’t been feeling well for a few weeks but doctors’ tests had revealed nothing unusual. One appointment at his GPs had been with a particularly unpopular doctor. Sam had told him he had blurred vision and as his job involved driving a delivery van had asked for a sick note. Sam came away angry and frustrated as the doctor gave him a sick note for only three days, virtually dismissing him as a malingerer. Over in the city, he booked into a hotel and was due to spend the week there. This was to be the day that changed his life. He remembers his legs feeling weak in the shop and his hand shaking when he went to reach for something from the shelves. The next thing he knew he was in an ambulance on the way to the city hospital. His wife was called and he spent the next few days disorientated, undergoing further examinations and scans in hospital. It transpired that he had a brain tumour, which was subsequently removed before him being sent home to convalesce. The removal of the tumour had led to a type of brain injury.

The whole experience left Sam with mixed emotions about his medical input. He had actually been fortunate in collapsing in the city. If this had happened in the rural town where they lived he may never had made it to the hospital in time. The aftercare back home was excellent, as was that of his own GP, but when he thought of the GP who had dismissed him as a malingerer, now knowing that he had a large brain tumour, he felt angry. Over the next few months and years he continued to be monitored with brain scans and saw a range of other health care staff. He underwent a cognitive test with a psychologist, the results of which explained why he found it difficult remembering things and multi-tasking. He asked his doctor if it was likely that he might loose some of his functions, thinking about an old friend who’d had a stroke and was now in a wheelchair. Of course he was given no guarantees. He became increasingly frustrated with life that led to a number of issues with mood and his marital relationship suffered as a result. He tried to think of the future and thought he had to make the most of the little time he had left. He didn’t want to waste anytime. He changed his lifestyle and gave up smoking and cut right back on his alcohol intake. Eventually he began to settle down.

One huge disappointment for Sam was the loss of his driving licence. He was asked by the authorities to give it up when he informed them of his diagnosis, despite him still feeling well enough to drive. This was with a heavy heart as he
considered himself an excellent driver, having driven for the shop, as well as having a taxi driving job beforehand. He began to rely on Rachel for lifts, whilst conscious that Rachel had her own health problems to deal with.

The idea of university learning had never left Sam and his thoughts began to return to this as a possibility. He’d never achieved what he believed he was possible of as a boy, when he’d forsaken his studies to spend time with his father. He didn’t begrudge his father those moments and would have given anything to spend more time with him, but the urge to study was still with him. He still had his love of history from school and he’d made progress over the years gaining some qualifications to enable him to be accepted onto a part-time degree course. The funding didn’t seem an issue when he applied this time around, which facilitated him enrolling on the programme. He made friends quickly on the course and he found it was something Rachel enjoyed being involved in too. She accompanied him on the local history trips and read and drank coffee in the University Library whilst Sam attended lectures. He worked hard and was successful in the first two years. He loved every minute of his studies.

Sam was especially keen on having a dog as a pet, as were Rachel and Tobias. Sam had had a dog when he was young; unusually for a family in a tough mining village, a little black poodle, but he loved her anyway. The three of them decided to see what they could find at the local pet rescue centre and soon selected the quietest dog in the pound, which was described as being wanted by nobody. Another dog followed on a second trip and the animals soon became an integral part of the family and dog walking part of Sam’s daily routine. Sam loved the chance to walk the dogs for miles in the countryside in solitude.

Sam’s brain scans were clear for over seven years. He began thinking his future must be fine, what with nothing untoward reported for a few years, yet at the back of his mind he always suspected that the tumour would return. Whenever he had a headache and mentioned it to anyone they tended to dismiss it but Sam knew that something wasn’t right about his health. One day he went for his scan results and could see by the look on his oncologist’s face that bad news was about to be delivered. The tumour had indeed returned. Sam felt just like the man on the television advertisement put out by the MacMillan Nursing charity; a man is walking between two hospital buildings and drops to his knees
as if someone has pulled the legs out from underneath him. He now knew he was right and those around him wrong when he had talked about his headaches. It involved a second major operation to remove the tumour and Sam didn’t actually think he would survive this event, but indeed he did. Radiotherapy followed. Sam coped with this by meditating whenever he went into the machine and found that he prayed for it to work, more than anything else, each time. He was left with coping with the side effects of the drugs and the pain from the scar on his head.

He had begun to work part-time due to his ill health but eventually this too became too fatiguing to contemplate; his life had become a round of working in the morning, sleeping in the afternoon, waking for his evening meal and being fatigued again in the evening. He was told that he would be on chemotherapy for the rest of his life and he made the decision to leave work. It seemed like the right time to leave the firm, as despite working there for twenty years, a takeover was imminent. He thought long and hard about making this decision and eventually decided that it was time for him to think about himself. He had always put others ahead of himself and now he wanted what time he had left, to do what he would like to do. Immediately he saw the benefits of making the decision by way of feeling much less stressed in his daily life. He wanted to have some time at home to enjoy with his family, especially his son, like his father had with him and to engage with his hobbies. He knew it would mean they would struggle financially and did worry about this a little. He wondered whether he should pay for his funeral at this point, to save any distress for Rachel when it came to finding the money for it at a later date. He thought back to how his own father had treated him and how much he valued the time together and this became a strong influence on wanting to spend more time with Tobias.

It was with regret that Sam made the decision to give up his degree course in history. He’s asked the doctor for a prognosis and potentially how long he may live. With four more years to go on the history degree he probably wouldn’t graduate with his prognosis. A compounding factor was the cognitive deficits that were making studying harder and as the course progressed the difficulty of the academic work increased. Rachel urged him to continue, as she knew it made him happy, but he was resolute about spending more time with his family, in the time he had left. He was very conscious of the clock ticking and time running out for him and he wanted to enjoy life.
Sam spends time each day with his hobbies, such as model making, embroidery and reading, whilst listening to classical music or Radio 4. He gets such pleasure from each of these and they help him relax and feel content. He attributes his pleasure in solitary pursuits to spending so much time alone as a boy, when his father was out and no-one else was in the home and he had to learn to entertain himself. He becomes impatient with Tobias if he complains of being a bored teenager and reminds him that at his age he lived in a house with virtually nothing and he was never bored! Whilst engaged in his cross stitch he likes to think that he is leaving something for Tobias when he has gone and that Tobias will look back on the work and think, “My Dad did that.” Sam is conscious that he was not able to have anything to remember his own father by, due to their family circumstances at the time and his father dying with no possessions to pass on.

Despite giving up his history course he knows he can still read about history and take Rachel on trips to places of local interest. Going further afield is a little more problematic; they have booked some holidays to places in the UK which Sam is looking forward too, but Rachel is urging him to still travel abroad. Sam is reluctant to travel by aeroplane as the last time he flew the flight adversely affected his brain and ears and it has brought on a concern for how he would fare on a future flight. There are still places he would like to visit, including one day seeing the beaches in Normandy where his father fought during the war.

Activities like tending to the garden are shared with Tobias doing the heavier work and they enjoy going to the cinema together. He follows a military theme with his model making, triggered by his father’s war stories as a boy. Similarly his cross-stitch patterns often follow the Apache theme, linked to his interest in cowboys and Indians as a child and supporting the underdog. He knows that some people laugh at a fully-grown man sewing but he finds it the best way to relax and reduce stress. Besides he is creating a legacy for Tobias to remember him by.

At times Sam does become despondent. He looks back over his life and the things he has endured and wonders why life has been so difficult for him. Suicide has entered his thoughts in the past but he doesn’t think it is something he could ever go through with. Instead he decides to, “Keep calm and carry on”
and just wishes to see Tobias through to adulthood, which he thinks he will manage. The future holds worries about loosing his functions, partly due to Rachel having her own health problems and Sam wonders how she might manage caring for him. He tries to be a good father to Tobias and offers him advice whilst not being authoritarian. Him and Rachel have always been upfront with Tobias about their ill health. They know that he worries but they would like him to be prepared for what the future holds.
Appendix R: Narrative Analysis

Participant 5 – Susan’s story

Susan always wanted to be a nurse, from being a young child. She grew up in a northern town with her mother, father and younger sister. When she was sixteen she set out to fulfill her desire to enter the nursing profession. She applied to the district hospital nurse cadet scheme in the nearby city. Imagine her disappointment when she was rejected with the words ‘not nursing material’ ringing in her ears! However, Susan was an optimist and quite determined and she was not to be deterred and applied further afield, this time successfully.

She completed her state enrolled nurse qualification, which led to opportunities to use this and travel: she and a friend set out to work in the Channel Islands. She stayed there for a year, but eventually decided to end the adventure and return to the north of England to settle closer to home. It was here that she met her husband John. John had been married before and he had a difficult experience in that his first wife had died suddenly of encephalitis, a form of acquired brain injury that, in this case, had been fatal. John was a graphic designer but he’d decided that he would like to try something different and so they moved to a rural town in the dales and offered bed and breakfast to visitors to the area.

Susan, meanwhile, continued with her nursing career. She had taken on a role as a community nurse and was surprised that the work entailed so much involvement with palliative care. She became quite used to dealing with the issues families had to cope with when going through difficult periods and she found that people often came to rely on her intervention, which she found very rewarding. The helping role involved in her nursing was very meaningful to her.

The work involved a lot of time spent driving, both to the area to work from the rural town in which she lived and in terms of the fact that she was a community nurse. A new opportunity came up that involved a secondment to a managerial role setting up a new hospice provision. She was not so eager to take on board but did so with encouragement of colleagues. This was a situation that moved Susan out of her comfort zone at work, where she had to take responsibility in setting up the unit from scratch and hiring a full team of people to work with. It moved her away from the direct patient contact in nursing to developing more
managerial skills. She learnt quite quickly that it was difficult to be able to please a whole team of people with differing perspectives in the workplace. Susan found the whole experience to be a very steep learning curve and not an experience that she would choose to repeat but something that she was proud of, in that she played a key role in setting up a brand new hospice service for the community where there had previously been none. They received very good feedback from patients and relatives which Susan found rewarding.

Eventually Susan decided to return to MacMillan nursing in the dales. A condition of the role involved Susan completing her nursing degree, again a challenge that she otherwise may not have taken on. She began her studies alongside the work in the community. Susan was someone who had always been fit and well to that point, healthy and well established as a nurse.

One particular day Susan was on duty and dealing with telephone calls as usual, she thought, yet one of her colleagues noticed something different about her manner on the telephone. This was the instance her life changed. One moment she was on the telephone, the next she was coming round on the office floor, surrounded by colleagues and to her huge embarrassment, her clothes were wet due to incontinence. Her colleagues helped her up, but must have shared her embarrassment at the incontinence as no one offered to bring her dry clothes. All Susan could think of was getting out of the embarrassing situation and as soon as John arrived she asked him for help to find something to change into. She was taken to the local district general hospital, before being transferred to a specialist hospital for a neurological investigation. It didn’t take long before a diagnosis of sub-arachnoid haemorrhage was made.

John was shocked as it was like history repeating itself; this was another form of acquired brain injury and the coincidence of this happening to two wives was something he wasn’t expecting. He was naturally very anxious. This was noticed by the hospital team and resulted in the consultant taking him aside to explain exactly what the situation was with his wife, which he very much appreciated. Susan obviously did not grasp the gravity of her situation initially: she was reminding John to do trivial things like cancel her hair appointment and postpone their planned weekend away by seven days. The situation was hampered from John as he didn’t drive and the hospital was a considerable
distance for the rural town in which they lived. Friends rallied round and there were plenty of offers from people to bring him to see Susan.

The experience of being a nurse in hospital as a patient was very enlightening for Susan and one that made her stop and think about how she may sometimes have acted with her own patients in the past. Firstly, she found that some nurses came nowhere near her, perhaps worried that she may ask difficult questions that they didn’t want to answer, delivering potential bad news. Others went over and above the call of duty, which she found comforting and reassuring. What Susan hadn’t done at this point was ask for her specific diagnosis: it was almost as if she feared hearing bad news and so avoided the issue. She likened this to patients she had nursed who avoided hearing the word ‘cancer’ and could relate to them now as she was wanting to hear a less serious sounding diagnosis than one she may potentially be told. One day she could ignore the issue no longer.

The doctor was visiting the ward with an entourage and she heard them discussing medical matters at the end of her bed, the experience of which alone she was intimidating. When she heard them say the words, ‘sub-arachnoid haemorrhage’ she looked to the bed opposite, thinking they must be talking about another person and was horrified when she realised it was her own diagnosis after all! The shock was like experiencing a second haemorrhage.

She kept thinking, “These things happen to other people. Not me, I’m the nurse”. She became acutely aware of further issues of depersonalisation from the nursing staff and felt she had become ‘the sub-arach in the corner’ and when an operation to try and treat the haemorrhage was unsuccessful she became ‘the failed embolisation’. At this point she kept thinking, “I do have a name” and then reflected that she’d done this herself as a nurse and accepted that on a ward you become just another number.

After a ten day stay in hospital Susan’s physical health had stabilised and she was discharged home. And that was simply that – she was discharged home with a promise of a follow-up appointment with the consultant in about six weeks time. Just before going home she enquired about a sick note for work and was shocked at the response of being offered one for three months as a preliminary measure! She hadn’t realised her recovery would be so slow.

She was also fearful as she didn’t have any advice about possible further symptoms and what to expect in terms of her illness experience once at home.
Nobody had warned her about the overwhelming fatigue that she came to experience. At times this caused her embarrassment as she wasn’t always aware that the fatigue led her to getting her words mixed up: for example, when she meant to say she had just seen a man with two dogs by the zebra crossing, she said she had just seen a man with two zebras by the crossing! Her husband used to see this as his indication that she was getting over tired. However, to Susan it meant more than that; it represented a loss of control, which she found frightening. Sometimes she went to bed for twenty-four hours and woke feeling no different. The effort required in taking a shower would render her unable to do anything else for an hour or so afterwards. Being unable to drive for three months post-ABI was another setback as she was the only driver in the household but it did encourage her husband to obtain his licence. These experiences combined had psychological consequences, as someone who had always worked and been busy her mood became low as a result. This was difficult for John, as he didn’t seem to know what he could do to remedy this or help. He suggested going away on holiday but Susan explained that her low mood wouldn’t go away: it would just go with them. They did go away for weekend breaks but big holidays weren’t something Susan could cope with.

Susan had missed her dog whilst in hospital and found to her surprise that now she was home the dog would come nowhere near her. The dog would sit across the room staring at her head, where her hair had been shaved and she wore a dressing. If Susan was alone in the house and she went upstairs to the bathroom she would come out to see her dog sat waiting for her, to ensure she got safely downstairs. She felt that her loving pet sensed that something was wrong.

They telephoned the hospital to see when the six-week post discharge appointment would be, only to be fobbed off by the consultant’s secretary, being told he was very busy. It actually took five months to be given an appointment. Susan had become involved as a participant in a research project and it was through this that they had access to some leaflets that explained, for the first time, potential symptoms she might experience post acquired brain injury. John found these particularly helpful and they read them together. Just having reinforcement that what Susan was experiencing was to be expected was hugely reassuring and almost normalised the experience. Not seeing a consultant for several months however left Susan feeling quite distressed and
she was left with the feeling that the aftercare response was along the lines of “It’s happened. It’s been rectified. Get on with your life.” It was almost as if by leaving the ward she was thought of as, “Well they’re gone.” However, having access to more information at the time would have really helped her cope much better at home.

Susan managed her own rehabilitation in that she gradually increased her daily activities. She began to do light housework but had no energy or motivation to cook or iron. Previously household chores had been shared with John but now she found it difficult to complete many of them. The lack of motivation to cook was further compounded by her senses of smell and taste being affected by the ABI and affecting her appetite. She had always been a dog-walker but walking her springer spaniel was too much and her GP advised against this, so instead she took short walks around the town in which she lived. Returning to driving was daunting at first, being behind the wheel of a car after a period of not driving, but she managed it well.

Friends would phone her and take her out for coffee in the car and she was very appreciative of their friendship and support. She was beginning to realise what true friendship meant and almost all were great, (but one reacted not so well). Her long-standing hairdresser phoned her up and came to her house on his day off to style her hair nicely for her, which she was touched by. A colleague who had previously been frosty was having her own treatment for cancer and made some friendship gestures she wasn’t expecting. However, her sister hadn’t been able to visit her for some time as she had taken badly to her older sister’s situation. She was quite a vulnerable younger sister and didn’t know how to cope with people being ill. Susan tried using social media to connect with others with ABI and found a chat room where people met, but withdrew after a while, as the comments posted weren’t helpful and not the type of thing that she would share.

She commenced a phased return to work starting about six months post-ABI, completed in twelve. She had been part way through the nursing degree programme at this point and was supported by the university to slow-track her way through the programme to be able to complete it. She hadn’t thought she would attend the graduation ceremony, as she was no longer with her peers but John persuaded her and she adored it, celebrating her achievement. It was also
important to her personally in being able to achieve something that required high-level cognitive skills when she’d had a brain injury. This had implications for her day-to-day working as some fellow nurses had been very supportive of her return yet she had felt some might have a prejudice against any type of brain injury. This was compounded by the fact that she displayed some outward physical features that were unusual in that her eyebrow was fixed and she felt the impact of this from some of her peers.

The fatigue of working full time took its toll and after much discussion with John, Susan decided to take early retirement. She took a few months off then decided to take a part-time nurse role in a hospice, which she enjoyed, not only because of the reduced hours but the role involved less stress. This continued for a while until some symptoms developed which she wasn’t expecting. The fatigue returned, this time intensely and she developed a tremor in her arm. She began to doubt her own ability to continue to carry out the role due to the physicality required and the subsequent safety element for the patients so she finished work at the hospice. With this came some self-esteem issues for Susan; she had had her nurse identity since sixteen years old and was now in her fifties and it was potentially slipping away from her. She still had the desire to help people and wanted to remain a registered nurse. Her friends had told her that she would make a good counselor and so she decided to pursue this as an option and enrolled on a counseling skills course. She also applied to undertake voluntary work at an information centre for MacMillan nursing.

Meanwhile, Susan knew that the fatigue and other symptoms were quite different to those of the sub-arachnoid haemorrhage but was struggling to get her GP to acknowledge this. She went back repeatedly for appointments, asking for different tests, some of which were done but revealed nothing exceptional. The GP told her emphatically that they were delayed brain injury symptoms. Her friends encouraged her to press further and even offered to accompany her to appointments. Being a long-serving healthcare worker Susan was aware of consequences of alienating healthcare staff so treaded a fine line here. What she wanted to say was that if she had been told what to expect in terms of brain injury symptoms she wouldn’t need to bother the GP, but she had been given no information post injury to make sense of her symptoms. She also felt a little let down in that she had been a nurse herself and had helped people with their healthcare for so many years and have personally invested so much, yet was
unable to get help for herself. Eventually John supported her on one visit and he surprised even Susan with his forcefulness, but to no avail. The doctor tried to politely tell her that it was an issue of not coping, rather than one of anything other than ABI. Then one day Susan had to have an emergency appointment with a new GP and he recognised immediately that something had been previously missed and made a neurology referral. The support she received this time around was exceptionally good. By this time she had convinced herself that she had multiple sclerosis but she was quickly given a diagnosis of Parkinson’s, confirmed by tests on the dopamine levels in her brain. What this enabled was prescription of medication and within two weeks the symptoms were gone. The neurologist explained that the previous diagnosis of ABI had been a ‘red herring’ that had led to the lack of medical intervention, but he thought this should have been spotted sooner. This difficult period also involved Susan’s dog having very poor health and needing to be put down. The GP discussed using anti-depressants as well, to help her over the initial period of diagnosis and she readily engaged with this as a temporary measure. Susan had never imagined she would have been the type of person to take anti-depressant medication but actually came to find it life-saving.

Today Susan is enjoying the counseling skills course and hoping to use this in a future setting helping people, but not in the field of palliative care or bereavement in which she previously worked as a nurse. She is also part way through the acceptance procedure as a volunteer with the MacMillan Cancer charity. This is important to her in terms of getting her self-esteem back and she has missed being part of a team at work. Being at home without the work role had left her bored and in a bit of a rut. She knows that she has a lot of knowledge, which could help people in terms of advice if they contact the MacMillan charity and being involved in this helping role is something that she has had taken away from her with the illness experience. When she was nursing people with cancer she sometimes felt out of her depth and would refer on to a counselor and now thinks counseling would be a good role for her. Her sister still finds it difficult to discuss Susan’s illness and certainly doesn’t discuss her secondary diagnosis. She is exercising in terms of swimming, Pilates and an exercise support group for people with Parkinson’s. She really enjoys her health club membership and it gives her opportunities to meet new people as well as the exercise being and important therapy for Parkinson’s. Still being able to drive is important to her to give her access to her daily activities, especially living
in a rural town as some of the places she goes regularly are much further afield. Hospital appointments are quite almost thirty miles away and these would be especially inaccessible if she didn’t drive. There is even talk of the clinic moving even further away. One of the benefits of living in the rural town however is that the people are very supportive and this was especially so when she was admitted to hospital and her husband needed lifts to visit.

She is proud of her display of patio plants that comes in the summer, which are colourful and healthy. They decorate the rear garden and this is a place that Susan and John relax on summer evenings, with a meal and glass of wine, weather permitting. She is back to taking an interest in cooking and is pleased that she can engage in household tasks that were too fatiguing a short while ago. She feels that her ABI symptoms had subsided a few years after the event but the secondary diagnosis is now the complicating factor of having to pace herself with her activities. They are planning to buy a mobile home in a beautiful seaside location for weekend getaways and plan to get another dog for company and to walk on the quiet beaches near to the mobile home. She finds dog walking therapeutic and people stop and talk when out with a dog, though she knows that she does have to pace herself.

Looking back she feels that the illness experience has brought her and John closer together and views life in terms of these things happening for a reason. This happened after the ABI but is still trying to understand the meaning of the acquiring a secondary diagnosis. She now understands the life view that some past patients had about living for today, something that she never previously related to.
Appendix R: Narrative analysis

Participant 6 – Hilary’s story

Hilary was born in a rural area of the north-west of England. Her father worked as an engineer in the mining industry. Her mother was a housewife (though probably a frustrated teacher of English). She wrote poetry and taught Hilary to read from an early age. Hilary had one brother. When Hilary was still young the family relocated to South Africa where her father took an opportunity in the gold mines. Life was quite different in South Africa: the family had servants, (during the Apartheid era) and they needed to keep guard dogs. Hilary felt like a novelty at the local school and was known as ‘the little foreign kid’. She quickly switched between her native English and Afrikaans and found languages easy to master. The garden had peach trees and a grapevine but there were lots of large spiders that Hilary detested and her mother was so scared of the earth tremors that they eventually returned home.

Back in England her newly found accent was yet again viewed as strange but it gave her a privileged position in school in that they did regular television broadcasts and hers was the voice that was selected due to it lacking a local accent. Even though her father was brought up on the local council estate, ironically he forbade his children from playing with the children there. Hilary was a keen swimmer and enjoyed creative pursuits, such as writing music and poetry. She was intelligent and enjoyed analysing issues in the Oxbridge Group at school. Her mother was keen for her to pursue the dream that she didn’t fulfill herself, to be an English teacher, but Hilary had a desire for a career helping people and chose pharmacy instead.

Living in an expansive rural area gave Hilary an opportunity to engage in a range of outdoor pursuits, such as fell walking and scuba diving. She was familiar with the names of many species of wildlife that visited the area where the family home was. Her father was a stereotypical male from a rural area in that he thought that a woman’s place was in the home, but Hilary was keen to break the gender stereotype. She took to riding a motorbike and then her father helped by offering advice from his engineering background and many a time had to come and rescue her when the bikes broke down.
Once working in pharmacy Hilary found it limiting in that there were few opportunities for promotion. She ventured into other careers, tried nursing (but became too emotionally attached) and then advertising; she was good at art and interested in psychology and wanted to see how the two subjects could be utilised to create demand for products. She found that she had a photographic memory and was able to memorise huge amounts of information.

She married and left work to have her first son. She experienced an episode of puerperal psychosis after her first pregnancy. A second son followed shortly after. Her choice of husband turned out to be wrong; he rarely allowed her to take the children out of their buggies as toddlers, was a gambler and violent towards her. Her sons grew up seeing this violence towards their mother. She tried to tell people about her husband’s physical abuse but she was disbelieved, due to having had mental health problems following the birth of her first son and people put it down to another psychosis. He cleverly only bruised her on parts of the body that were covered by clothing. Her savings evaporated with her husband’s gambling habit. She developed epilepsy and was forced out of a hospital job because of this. Her strong work ethic and resilience wasn’t going to let this prevent her from earning and she juggled her roles with three part-time jobs as a result. Working was very important to her not only financially but it gave her an identity. She felt that one of the first things people ask when first meeting is ‘what do you do?’ and was brought up with this work ethic.

She eventually got out of the marriage, leaving the children behind, but she felt sure her husband wouldn’t direct his violence towards them. Years of being rubbed by her husband meant that her self-esteem was so low that she could hardly raise her head. Her husband refused a divorce even after two year’s separation but she had met another man by this time. They became engaged but had to wait a full five years separated from her first husband before he would allow the divorce, much to her annoyance. She was much happier in this second relationship. This new partner was deaf but was able to lip-read. They functioned well as a couple as she could deal with his telephone calls and was happy to help him. They had begun buying a house together when a year later she was taken ill.
Hilary was taken to the local hospital and observed overnight. By the time they undertook a brain scan the next day, some damage had almost certainly been done. They diagnosed a brain haemorrhage. She was moved to a regional specialist centre for surgery and remained in a coma for three months. She contracted MRSA and was eventually discharged to a rehabilitation hospital.

Her mother had had two heart attacks whilst she had been in the brain injury coma. Hilary was very worried about her mother’s health and tried to offer advice from her long held medical knowledge from pharmacy. This was to no avail and was met with blame from her father, who saw his wife’s stress of having a daughter like Hilary, being the root cause of the heart attack. Hilary thought this was unjustified, as she didn’t invite her own illness issues. She couldn’t get to visit her either due to poor public transport. The blame from her father did make her feel some responsibility for her mother though.

Some of the symptoms she experienced caused extreme frustration. She could hear the words she wanted to say in her head but couldn’t communicate them. She screamed as a result. She felt locked in her own little world, behind an imaginary glass wall. She couldn’t walk at first but eventually she made progress with this. Her symptoms were complex and didn’t follow a familiar pattern. One of her main problems was sequencing. Once-familiar tasks that she could do since being a small child, such as washing and dressing were now unfamiliar to her. She could no longer make a cup of tea. Her attention span had dwindled. A downside to being in the hospital was the fact that most of the patients went into a room to smoke. Hilary thought she’d go in and not smoke, but soon succumbed and became addicted.

Once she was discharged home she continued to receive rehabilitation in the community. Her memory was severely affected and she found it hard to understand how she could walk into a room to do something and then forgot what she had gone for, the moment she entered the room. It was a ‘light bulb moment’ when the occupational therapist explained she had short-term memory issues due to not being able to retain information. ‘Now’, thought Hilary, ‘I’m the one receiving the information and being helped when in the past I’ve always been the one helping and giving the information!’
One of the symptoms was having lost social skills in communication, in that she now automatically would tell people exactly what she thought about them, rather than give a socially acceptable response to questions. This she found mortifying when she realised the consequences. She called this ‘having to learn to lie’ and edit her speech again. Simple tasks like standing at the sink to wash the dishes were now complex to her, as she didn’t know the sequence of putting in the plug, turning on the tap etc.

After a year Hilary was still making progress but not fully recovered. Some of the tasks she previously helped her fiancé with she could no longer do, such as passing on details from telephone calls. Thus she became redundant in her previous role of being of assistance to him. She could no longer hold a conversation and write down the details. She and her fiancé went to a wedding of one of his family members. Hilary was still having mobility issues and when she staggered down the aisle her fiancé tried to cover his embarrassment and said that she was drunk rather than disabled. His family had come to believe that she was faking her symptoms as she had retained her proficiency in some matters, such as detail in long-term memory, but was not at all proficient in others. It was then that he took Hilary to her parents, many miles away in a remote rural area on the other side of the country and said he was leaving her there for the weekend. He never came back.

Here she found herself, with mobility issues, now living in a remote rural area with no local shops, no pavements and little public transport. Ironically she could still name the local birdlife, having been brought up in the area and retaining long-term memory, but unable to carry out basic tasks. She found her parents to be over-protective, for example when she tried to use a knife for eating they were scared that she may cut herself. She wanted to be able to try things for herself and found that she was only allowed to do this on visits to her brother, whose wife worked in a nursing home and she recognised the issue. Due to the nature of the local authority boundaries if she had applied for housing in her parents locality she would have ended up being housed many miles away in one of a few towns in significant decline where she didn’t know anyone. When there was nowhere to place her she ended up in health services on a mental health ward, which was totally unsuitable for someone with brain injury symptoms, as they just weren’t understood. The experience was compounded by hurful nursing staff, who mocked her lack of function and her speech and said she
sounded like an animal. She and her father reported the injustice to the hospital authorities.

The only place offered to her was in a facility owned by a nursing home group that also had a specialist home for people with brain injuries. She agreed to go as it was in the area of the country closer to her sons and where she wished to be. Also there was the hope of a transfer to a specialist brain injury home. However, the home she was placed in was actually for elderly people with dementia and she was only in her forties! She found the experience quite scary at first. One neighbour had been a convicted sex offender and she hadn’t been told about this. She found out one day when she delivered some shopping and found him looking at inappropriate photographs. She told the care home staff who said that they knew but Hilary was still worried and warned her sons about having any contact with him when they visited. Her other neighbour was very violent. However, she remained relatively patient in the home, despite the specialist brain injury bed never materialising, and was allowed special privileges due to being able to find her way around the local area and go to the shops. She decided to implement some of her own coping strategies around being orientated to the day of the week and established the habit of going out each day to buy a newspaper. This habit turned to irritation when the other residents began to prompt her to pop out to buy ‘our paper’ so she switched to buying a television magazine and ensuring she turned the page over each new day. She observed shortcomings in the care home staff but understood how this came about; they were perfectly nice and sometimes went out of their way to drop by on their day off but an organisation paying the minimum wage would only ever attract untrained staff. All of this time she had no support from the social services department and her father contacted the ombudsman to rectify this.

Hilary began to hear about the brain injury charity, Headway but there was no local branch. The nearest one was about thirty miles away but she worked out a way to be able to get there by public transport, even if it meant waiting around in one of the bus stations en route; there was a café there in which to wait. A group of interested people began to look at setting up another branch and Hilary was pleased to become involved to help and become part of the steering committee. This was a success and the branch achieved its own charity status and gave Hilary a certain amount of pride in her helping role.
Eventually the money to support Hilary living in the care home dried up and she was asked to start to look for somewhere else to live. However, she didn’t know how to do this, bearing in mind her brain injury symptoms, both cognitive and physical. Her father intervened and they sought assistance from the Carers’ Association to force the local social services department to provide some sort of support. However, the services didn’t seem to operate joined up thinking. She was told there was a grant to buy furniture for a local authority house she had been offered, but to choose the furniture she would have had to make her way to an industrial estate quite some miles away that was inaccessible. She did get to move to a local authority house, in a small rural village, which she was pleased about. The outcome of the care home experience was so awful that she dreaded ever having to go into similar care at some point in her future life.

Hilary was now living in a local authority house with her sons being able to stay some of the time. She still owned half a house with her clothes and furniture in it, but couldn’t access it with her ex-fiancé there and no means of removing her belongings. Home care was provided but it didn’t suit her needs. The carer was given thirty minutes a day to help her. This included time to get her out of bed, get her washed and dressed and sort her tablets. Thirty minutes just wasn’t sufficient and certainly didn’t allow time for Hilary to relearn tasks with help. Hilary didn’t want everything done for her, she wanted to learn and progress so as she could work towards independence. Eventually she dismissed the service, cross that she hadn’t been given choice about it. She was then able to have a few hours a week of a support worker visiting from private neurological rehabilitation service. This was so much better as the rehabilitation element was considered and they worked on specific issues, such as washing and what prompts were required for Hilary to do this independently. She did find it embarrassing having to let someone know she required assistance for very basic daily living tasks.

The rural village suited her well as the paths were flat and there were good public transport links. However, there were times when the bus drivers were reluctant to allow her onto the buses and she was upset at their attitude. This was because her unsteady gait could be mistaken for drunkenness. It was a fairly regular occurrence and when she discussed it with her father he dismissed it as part of her imagination. Then one day, when she was staying with her
parents her father heard a couple discussing his daughter in a car park and saying how disgusting it was being drunk at nine o’clock in the morning. At last he believed her! However, living in a location as rural as where her parents lived would not have suited her at all; the public transport really was inadequate and their village did not even have pavements to cope with her awkward gait. Hilary’s village also had two local policemen that came to know her, which she found reassuring. At one point she kept locking herself out of the house and they came to her assistance, plus on one episode of locking herself in.

The local buses from her village took her to the local town or a nearby city. The local town was always difficult to walk around, as it was built on a hill. Hilary’s mobility issues were compounded when walking up hills due to falling forward. Ramps caused the same difficulty. However, she persevered as going out to shop became part of a routine and got her out of the house. Shopping was often a challenge; she made a list but as she went from shop to shop she couldn’t remember what had and hadn’t been bought from the list and sometimes bought the same things several times over. She was pleased she didn’t live in the town though, due to geography issues. If she shopped in the city she was able to use a mobility scooter service as otherwise she feared being knocked over in crowds. Hilary attempted to visit her parents a lot less frequently than she would have liked as the public transport links to their remote rural home didn’t link up well with the connections to her own home.

The relationship with her sons deteriorated. She was forced to move house because of benefit changes and the introduction of the Bedroom Tax. A company was hired to move her belongings and her papers became mixed up in the move. As Hilary could no longer sort information and categorise she couldn’t easily find the information of her sons’ contact details. Her oldest son had Asperger’s Syndrome and visited occasionally, for example with a Mother’s Day card, but she had an irretrievable breakdown with her youngest son: she offered him some financial support but he demanded more, over a mobile phone, which Hilary didn’t have resources for. Having had years of watching his father’s violent behaviour towards her he began to emulate it and Hilary became frightened. Having told her brother about the behaviour, he came with her father to remove her son from the home and she lost contact with him.
Hilary found it lonely by herself. The loneliness was exacerbated by sometimes not wanting to go out in public due to hurtful comments. Her sons were now adults and her family lived on the other side of the country. She had always loved animals and had had pets at home in her youth, but didn’t think she could cope with her own dog. A charity visitor to the house mentioned that her cat was having kittens and Hilary saw this as an opportunity to have her own pet. She named the kitten ‘Joanne’ only to rename it ‘Joseph’ when she realised it was a tomcat. She took responsible care for him and ensured he was vaccinated and neutered and enjoyed having something to care for and have a relationship with. She was very aware of the health benefits of pet-care and knew that pets could help lower blood pressure too.

Part of Hilary's difficulties involved handling money. She came up with the idea of having her money sorted into bags of one pound by her support worker and the local village shop became familiar with her system. Hilary found it easier to count the single bags than pounds and pence. This was one of the advantages of living in a small community in which she was known, though that didn’t stop rumours about her unsteady gait being down to drunkenness. Some of the shops in the local town were less supportive of shoppers who needed extra time or help. Also, because she frequently forgot items when shopping, having a small shop around the corner was ideal for her and she could pop back. Being known to the shop and them understanding her difficulties allowed her to ask them to add money to her mobile phone as she struggled with recorded message instructions when she tried to do this herself. The shop was also happy to deliver some things for her, which probably wouldn't happen in a larger urban area.

She decided to try and improve her fine motor control by doing online surveys on her laptop, provided by a charity. She found this not only a purposeful way of working on the skills but she could also get financial reward for taking part. Her computer was also useful for social networking. She could keep contact with her family through Facebook and she also made new friends through games such as ‘Farmville’. She found this both sociable and therapeutic. A learning and support centre in the local town offered a computer course to Hilary where she could further develop her skills at her own pace. She enjoyed going there for the learning aspect as well as the social aspect. Additionally it was a female-only
environment and she felt safe, as she had lost faith in males to an extent after her past life experiences.

The support workers from the private rehabilitation firm gave the right kind of support in that what she needed was to be shown what to do so as she could relearn, rather than just having things done for her. Several months after her house move she still had belongings in boxes and needed help to sort through them and the support workers assisted her with this. Being a long-term user of social and benefit services meant that she had accumulated a lot of paperwork over the years, yet sorting and categorising were skills she no longer had. They helped her with other tasks that required a sequence, such as changing the bed sheets; she found it embarrassing, having to now have someone to help her with personal tasks such as this. They made out cards of instructions for many simple daily living tasks, such as getting washed or using household equipment. These were useful in the home but not really useable for the same tasks elsewhere, for example getting dressed at the swimming baths, where there was no opportunity to lay all of the clothes out in front of her. In return she liked to help her support workers by passing on her knowledge of pharmacy generics, with advice as to how to buy cheaper medication than branded products. She also did this for other people she met. She once came across a woman in the local town who had become distressed coughing and had no money. Hilary identified it as a dry cough and went off to fetch some medication for her. The woman thus always remembered her and continued to talk to her on trips to town when they met and remarked if she thought Hilary was making improvement, even if small.

She found it quicker to learn tasks by remembering shapes and colours. When she first moved house the shower controls were a different shape to what she was used to and she had to relearn using the shower. The organiser from the head injury charity was a huge support to her and sometimes there were jobs that she had no one to help with, such as moving her washing machine, which he’d help with. She tried a system of getting visitors to the house to write their visit in a log book, so she could remember who had been, but sometimes she forget to make it available.

The local authority and housing association began a novel way of communicating information by way of a magazine to inform people of changes
to services and ways of working. This caused a difficulty for Hilary in that information appeared buried in the detail and lost within extraneous information. The previous method of sending a letter to inform people of changes was much clearer to her and something that she missed.

Reading novels was a long held favourite pastime of Hilary’s; she had learnt to read by the age of three. She was a big fan of Terry Pratchett stories and ordered them online from the local library then collected them on a trip to town. She especially liked to read in bed and found it was pure escapism. She also took a keen interest in politics and followed parliamentary debates online and discussed them with her support workers. She felt strongly that it was important to engage with politics to make wise decisions about who to vote for, knowing that who was in government affected so many aspects of daily life. She valued female equality, having seen developments in this since growing up and coming from a family and rural area, which was male dominated.

Having been a keen musician from a young age Hilary was trying to relearn to play the guitar. This was proving difficult. She still knew the chords in her head but somehow couldn’t convert them into the skill of playing them. However she was persevering and this phenomenon was apparent some time ago in walking and eventually she mastered this skill, so she believed playing the guitar must follow eventually.

Hilary had twelve different social workers in five years, often not being told when one had left and another one taking over her care. At one point they even took her bank account off her leaving her with no access to money for food. Changes to the benefit system continued to make Hilary’s life stressful. She was prescribed Valium by her GP. She developed alopecia and took to wearing a wig. This meant that some activities she would have liked to do were now off limits to her. For example, if she tried to swim in the public swimming baths people would stare at her. She was able to access a specialist pool at a resource for people with neurological conditions, where she was socially acceptable, but this opportunity didn’t arise often. She felt naked without hair and didn’t want people to feel sorry for her as they often assumed she had cancer. She imagined that her hair wouldn’t grow back quickly as dealing with the benefits agency was so complex for her.
Her deterioration in health was also keeping her from being on the steering committee of the local brain injury charity. She did try and attend the annual weekend away that the head injury charity ran in the region, which was an opportunity to feel normal again and take part in all sorts of adventurous activities in a supported way. In the past she had tried a ‘KingSwing’ free fall jump and found this to be a real opportunity to build confidence.

A drive was being made to tighten up on people with disabilities increasingly returning to work or having their benefits cut. Hilary’s dilemma was that elements of her past extensive knowledge and memory were evident and made her sound competent, yet she had some very real cognitive deficits that would prevent her from taking on work that were hard to convince the benefits agency of. She had imagined that she would be back to work at this point, ten years post injury, but it just wasn’t likely. For example she had poor retention and short-term memory and couldn't categorise or sequence. Any voluntary work she had tried hadn't been suitable, primarily due to the categorising and addition deficits. However, it was difficult to portray this to the benefits agency when she was able to easily relay such as her national insurance number, that was implanted in her long term memory. All in all this made Hilary feel like more and more hurdles to recovery were being put in her way. She knew that if she had savings she wouldn’t turn to the state for support, but her first husband had gambled them away. At times she even thought it would have been better if they hadn’t kept her alive when she had the brain haemorrhage all those years ago. Sometimes life was like a big fight against the authorities, past partners etc. with people saying, ‘Well you sound okay’. She really wished the government would think these complex issues through.

Although Hilary had made relatively large steps in progress initially this was now less marked. She didn’t like to think about progress long term, as the prospect of bridging the huge gap between where she was before and where was now was daunting. However, people did tell her she was slowly improving and she viewed it as like ‘nibbling away at a huge piece of cheese’. She saw her life like climbing a ladder with some of the rungs missing. She still loved learning and thought it ironic that God had put her in a position where she needed to learn for so long, with memory problems, having had such a good memory beforehand. She thought she was developing a large chip on her shoulder, due to all of the nasty experiences she had had with people. She really took this to heart, as she was
someone who liked to treat people respectfully and expected people to treat her the same way. It made her annoyed but not sorry for herself. She believed she was working really hard to try and relearn what she had lost, but others didn't always see it that way. Having an almost invisible disability was hard, always explaining to people, though a charity card to show people offered some explanation in public. In her head she still saw herself as the person she was before, able to fell walk and do the things she always used to do, but actually no longer could.

Looking back Hilary was aware that some people with acquired brain injury had referred to the hospital where they took ill to seek compensation for negligence. This wasn't something that she ever felt she would do. Having worked in hospitals herself she was fully aware that mistakes do happen. She continued to want to help and make a difference to people. This was one of the reasons she agreed to take part in the research. She knew it wouldn't directly help her but was hoping in some way it may make a difference to those coming along behind her and that gave her a real sense of satisfaction.
Appendix R: Narrative analysis

Participant 7 - Helen’s story

Helen grew up in the scenically beautiful Lake District with her mother and brother. Her parents were married but she saw significantly less of her father as he worked a distance away and family visits were limited to weekends. She found her father emotionally distant for most of her life. She longed to have a father who was warm and affectionate, just like she’d seen in films but this was not to be. She now lives in a rural ex-mining village that is well served by transport links to nearby conurbations. She works as a nurse and is married to Dave and they have two pre-teen children. Dave had a brain injury four years ago.

She was introduced to her husband as a pen-friend when she was about seventeen. This was the time she was deciding to apply for nurse training and as she knew people in the north-east close to where Dave lived she decided to apply to train in the area. They began dating when she was eighteen and he was the only real boyfriend that she ever had.

Dave was in the merchant navy, working as a chef and this meant six-month periods away from home and they soon settled in to a pattern in the relationship that suited them both. There were even a few opportunities when Helen was allowed to accompany Dave on his sea trips and help out in the ship’s kitchen with him and she enjoyed this time spent together with him. She got to visit Norway and the Netherlands and even though they worked long hours on board ship she did enjoy being with Dave. They married when Helen was in her early twenties. Neither Helen nor Dave wanted to begin a family whilst Dave was spending time away at sea, so they made a decision after a few years for Dave to give up this career and find a job closer to home. Once Dave was back on dry land they had two children together, Tom and Emily. Helen continued with her nursing career and Dave worked as nursery nurse. Dave was someone who was always very ‘hands-on’ with sharing the childcare and his intelligence stood out and the way he could always remember things. He was exceptionally well organised, which was very unlike Helen herself, who tended to be more of a dreamer. This difference in personality worked well to an extent but it did lead to
Helen sometimes being on the receiving end of Dave’s criticism and he did get annoyed with her at times because of the way she did things.

By the time Dave was in his early forties they had been married for nearly twenty years. One weekend he began to have severe headaches and problems with his vision. They went back and forth to the hospital, concerned at this, only for Dave to eventually be admitted for investigation. It transpired that the visual problems were due to Dave having had a cerebral vascular accident, or, stroke. It was ironic that the incident happened on April Fool’s Day, as the realisation of what had happened to Dave came as an enormous and unwanted surprise to Helen. Once he was stabilised in hospital his discharge home was planned. Helen was shocked when she realised that there was no additional support being planned for his return home, especially as she was a nurse on the ward and she always assumed that provision was in place for people going home.

Her reaction to Dave’s unexpected illness was quite traumatic, in that she moved into a phase of hyperactivity and making irrational decisions. She exhausted herself with organising in the home and planning events with the children, such as decorating the garden shed and having special meals there with them. She telephoned friends at unsociable hours to chat to them. With her nursing background and knowledge of rehabilitation she busily planned activities for Dave to begin when he came home. She had never been religious but thought that if she spread the word about her husband being ill, even to relative strangers in the local community, she could get them to write a card to him and pray, hoping for the power of collective prayer. She asked strangers to help her by walking their dog, all things she would never have done under usual circumstances. She had never been a tidy person in the past but she tried to use tidying the house as a means of being in control and this helped her cope and she lived in this state of elevated mood. At this time she began to interpret events and coincidences as psychic experiences, such as wanting to meet a friend to talk to and bumping in to her otherwise unexpectedly.

Once home the extent of Dave’s cognitive difficulties unfolded. Alongside the visual problems he had memory deficits and although he could write he could no longer read, which was due to the specific site of the brain lesion in the corpus callosum. He seemed to no longer be his well-organised self. This actually had benefits for Helen in that now he seemed to be more like her at times, but the
downside was that she was now expected to be the organiser in the family. Cooking had always been Dave’s domain in the home but he struggled with this now and Helen had to step in to this role too, which was not easy at first. Family driving had always been Dave’s role but a diagnosis of seizures ruled this out and Helen had to become the family driver. This came as a huge disappointment to Dave as it impinged on his male identity as family driver. These additional roles initially became a cause of anxiety for Helen; preparing for family holidays in the car had always involved Dave as organiser and driver but now it fell to Helen, which she found difficult and stressful. Dave could no longer organise and pack the car and became frustrated. He was critical of Helen’s driving. The additional pressure on Helen caused her to crash the car on two consecutive holidays.

Dave’s rehabilitation became a preoccupation for Helen. He resolutely refused to engage with any of the activities she had planned, much to Helen’s disappointment. He seemed content to stay at home with a simple life of walking the dog and collecting the children from school, much at odds with what Helen felt happy with. The dog became crucial in helping Dave through this difficult period and Helen felt somewhat rejected and became jealous of the dog that seemed to be the main receiver of affection. He couldn’t return to his work as a nursery nurse as his memory impairment prevented him from remembering the children’s names and he could no longer read to them. Helen felt that it was wrong for Dave to stay at home all day. She tried to think of as many solutions as she could to find a place that he could go during the day, which would help with his rehabilitation but also she couldn’t bear the thought of him being at home, unproductive all day, as a man, whilst she went out to work. She suggested him volunteering at various local venues and charities, such as a museum and a pet shelter. None of this came to fruition. This was due to a combination of Dave not recognising that it was a problem and his specific cognitive impairments making volunteering activities difficult. It was a visit to a vocational rehabilitation charity that eventually relieved this anxiety for her; a vocation didn’t materialise from the visit but referral to a social worker did and this instigated monies for a paid carer to spend so many hours each week with Dave, who could take him out and involve him in various everyday activities, such as home repairs and manage bills.
Psychologically Dave didn’t take well to losing so much of what he was capable of and previous roles. Helen lived through a period of Dave being volatile and frustrated. He now had visual problems that impaired his everyday life and he struggled to cope with his memory problems. His medication affected their intimate relationship, which was a concern for them both, in terms of disappointment for Dave and making Helen feel guilty for this being less of a part of their marital relationship. On outings Helen was protective and avoided highlighting his deficits, such as him pointing out a new restaurant in the local area, when in fact it had been there for years. He had to ask her if he smoked, which in the past he did occasionally, but he couldn’t remember. This was a difficult time for Helen and it was her experience as nurse that helped her cope and got her through this difficult time.

Dave turned some of the violence on himself and began to talk about suicide. Now Helen was concerned to go to work in case he carried this out whilst she was away from home. People made assurances about how his situation could be much worse, which both he and Helen saw as them not understanding the psychological pain that the brain injury brought. She empathised with him entirely as she recognised that he could no longer do many of the things he could pre-injury. He also talked about leaving the family home. His low mood was aggravated by the death of his dog. Work colleagues and family helped her through this difficult period with reassurances that he couldn’t cope outside of the family home now more than ever but also that suicide may be his preferred option for life but she couldn’t prevent him from this if indeed it was his intent. Outwardly he put on a positive front to people but inwardly she knew that he’d lost some of his desire for life.

Helen continued her work as a nurse, even though initially Dave’s brain injury did affect her work performance. This was hinted at at work, though her seniors never challenged her directly about it. She had expected more support and understanding having worked there for so long with the same senior staff but eventually this settled into a pattern of her being able to work less shifts but longer, so as to manage childcare between herself and Dave. At times Helen acted in the nurse role at home, not only in trying to rehabilitate but also as a means of coping and trying to counsel her husband. This angered Dave and he made this clear, saying she ‘had her nurses hat on’ which she found hard as she was continuing to be caring and well-intentioned, trying to improve the home
situation. At times she did feel like she was less of a wife and sometimes a mother to Dave as well.

Helen and Dave began attending meetings of the Headway charity, which was more beneficial for Helen than Dave. This was life-changing and opened up new opportunities that otherwise she wouldn’t have experienced as a shy person. First she attended a national meeting, joking that she may be identified as a person with a brain injury. It was here that she began talking to others in similar or far worse situations than herself and encouraged one man to set up activities more locally. She was also able to relax and unwind at the social events. She then began attending local events and volunteered for activities she would never have tried otherwise. She attempted a high rope adventure activity, raised money by completing a zip wire challenge and enjoyed greeting new members and making them feel welcome at local meetings.

Currently Dave attends a local further education college part-time during the day, which Helen sees as progress and ensures that he is not at home all day and everyday. It does mean that she doesn’t get as much time to spend alone with him as she would like, with working her long shifts, but at other times she sees this as respite and an opportunity to find some personal space. Dave has his paid carer for ten hours a week. Helen thinks she should be doing more in terms of campaigning and raising the profile of people with brain injury following as incident Dave had whilst out with his carer, attempting to purchase some electrical goods. The lack of patience and understanding of the shop assistant infuriated Helen when she heard about it that she wrote a letter of complaint to the head office and she would like to do more of this awareness raising.

Family routines continue with Dave back to taking an active childcare role, prompting the children with their homework and collecting the children from school, although he does need prompting sometimes. The brain injury brings with it fatigue and if he falls asleep he may not wake up at the correct time. Dave is a good father to his children and they are well-supported by a local child-minder. He is actively involved in instigating family routines, such as making traditional cakes and puddings at Christmas, supported by family. He accompanies Helen in taking the children to after-school activities such as cubs. Family routines have settled down and compensatory techniques have been adopted, such as Dave wearing headphones to hear more clearly whilst
watching television and the children sometimes join in with this. It does limit conversation and communication but is now accepted.

Helen recognises small improvements in Dave’s cognitive abilities and is disappointed if medical staff fail to acknowledge this. The organisation of healthcare services can be frustrating too: Dave sees a psychiatrist to monitor his mood, but the psychiatrist doesn’t understand the nuances of cognitive issues for a man with a brain injury and interpretation of the situation can be made wrongly.

The children, although pre-teen, recognise the changes in their father and sometimes comment to Helen about it. Experiencing disability in the family has brought its benefits and made the children more caring as a result and raised their awareness of disability. They have more understanding and appreciation of others as a result.

Whilst at work Helen comes in to contact with many relatives of patients who have had a stroke like Dave. Now she has a new understanding of their situation, experiencing it herself. This helps her in her role to be a better nurse, but she has to stop herself at times from opening up to them about her situation. She is very aware of the situation being difficult for relatives as well as the patient now. However, she is disappointed about a lack of support when people return home from the ward. She is frustrated in the way the nurse role has changed over the years, in that she gets less time for caring for patients and spends more time on procedural tasks, such as administering medication. She would like to have an opportunity to undertake more one to one with people and so has begun to train to be a Reiki therapist. She does this with friends and the family and has enjoys this role as healer. She hopes to take the training further in the future and perhaps become a practicing therapist.

Currently, standing in the way of completing her training is lack of time for herself, mainly as working mother of two children but also as a wife to a man that requires additional support. If she does have some time to herself she enjoys the natural environment of the beach and walking with the wind blowing in her hair and collecting beach glass and admiring their colours. However, opportunities for this are few and far between. Sometimes she thinks she should be giving time to her friend but sacrifices this to enable to have some personal
space to spend time on her own. She’d like to spend more time doing activities with the children. The family does have a shared hobby of collecting and creating dolls’ houses. Dave does this with the two children and Helen doesn’t have her own doll’s house but joins in by decorating and admiring them. Helen keeps planning to get involved in creative activities but being busy and becoming distracted prevents this at the moment.

Four years since her husband’s brain injury Helen can now see some benefits as well as recognising the negative aspects of her husband’s illness experience. She embraces the new responsibilities of cooking, driving and organising as they are new skills that she previously avoided. She is pleased that Dave’s family acknowledges that she has coped with being married to Dave and the support he requires. A friend of her father’s has told her that her father is proud of the person she is and that he respects her for coping. This is acknowledgement she didn’t expect from her emotionally distant father. However, every day that passes Helen’s thoughts return to the time of her husband’s brain injury and the effects that this has had on the life of her family. Sometimes she wishes for it to all disappear. She worries about him having another stroke and his suicidal ideation. She sees Dave as still essentially the same person, in some ways changed for the better as he is calmer and less regimented than before his injury, but less so in other ways. She once held a notion that a life-changing event such as brain injury can bring personal growth and new opportunities and whilst this has occurred to some extent for herself it hasn’t for her husband, which she was hoping for as some sort of compensation for his losses.
Appendix R: Narrative analysis

Participant 8 – Christopher’s story

Christopher grew up in a close family in a rural town, with his Mum, Dad and sister. He held a keen interest in cars from being a child, through his Dad and grandfather, just sitting alongside them in the car and them taking him to watch events with cars and motorbikes. When other children were out playing football he was out on his bike, forming the beginning of his fascination with wheels, cars and engines. It felt like motorsports were in his blood. He became fanatical about rally driving and he gained a nickname, ‘Rally Chris’: his dream was one day to become a rally driver himself, if he had the financial means. He loved outdoor activities such as sailing, which he did with his school in France and this led him and his friends to take up windsurfing as teenagers. He enjoyed mountain biking and was highly active and fit.

On leaving school he took a job as an apprentice draughtsman. The atmosphere was oppressive, working in a Nissen hut with lots of contract workers who were heavy smokers. He took the chance to gain some further qualifications and gained an HNC in mechanical engineering. He was enjoying life, what with his windsurfing and his first car, a VW Beetle. He dreamed of one day having the Beetle’s ‘older brother’, the Porsche 911!

Off he went to Polytechnic to study for a degree in engineering. He loved living the student life. He took the opportunity to use one of his summer vacations working and seeing the sights in the USA and gained a really valuable experience travelling independently and meeting people along the way. His hopes and aspirations were to return to the USA in the future to work in the aerospace industry for NASA. He finished his degree and was offered jobs in the aerospace industry in the UK but he didn’t want to pass up the challenge to study for a PhD, and this was the option he selected.

He collapsed on campus a week into his PhD. He was 24 years old. He returned home to find out what the cause of his eyesight problems. The optician detected a problem, which set the ball rolling for a diagnosis of brain tumour. This was a frightening time and knew it would involve surgery, but with his engineering
background, he knew he could put his faith in medical technology and he would be fine. He had two neurological operations, one of which involved removal of the posterior fossa, which turned out to be malignant and would require radiotherapy. In his emotional state he pushed for hospital discharge earlier than advised. As the effects of surgery were wearing off he had the extremely frightening experience of visual fits: bizarre black waves washing over him, flames licking his face and a white building cleverly dissolving brick by brick in front of his eyes. Luckily after the third one these ceased for good. He was home for two weeks then experienced a stroke.

The world had been his oyster and now, he thought, it was all gone. This was the start of being passed through many sets of hands in the healthcare services. Hospital experiences weren’t good. Physiotherapy wasn’t great and occupational therapy seemed worse: so long as he was able to make a drink and snack it was considered he was deemed fit for the world. One strange experience he will always remember: he was asked to describe a photograph of a scene with a Range Rover and found himself unable to answer. The words were in his head but he felt locked in. The photograph was taken away and nothing said by either party. That was the first time he realised that his cognitive functioning was affected. The long line of hands eventually stopped and he was ‘out on the street’ and had to find his own direction and learn things for himself, something that he thought needed to be greatly improved.

Christopher’s and his parent’s plight led him to feel like he had fallen through a trapdoor and inside, it was a dark, dark place. He still felt like the same person but he didn’t have the life he had before. It was hard for him but it was hard for his family too. They pulled together as a family, but Christopher was lost as to where he was heading. His future had gone out of the window and they had to stop dreaming of the old future and had to get to grips with looking forward. His parents were very good and kept saying that they loved him. His father decided to seize the moment, to stop Christopher’s physical problems from getting any worse and they were aware that his walking was weak. He bought a book on recuperating from stroke and set up a self-physiotherapy programme for Christopher. They started doing exercises on the living room floor to improve his prospects. Through a work contact they had access to a running track that had periods when it wasn’t being used and Christopher was allowed access to it to practice running, without an audience. He did his best with what he was
presented with but realised he had a dead area of his brain and would remain a one-handed person and has no regrets about how hard he tried.

Christopher found himself in a place where no one had really gone before and he had to forge his own path. It was as though there was a lack of ‘neuro-culture’ to draw on and advise him or relate to. He found himself in a flat spin he couldn’t get out of. It was like being on a roundabout spinning so fast he couldn’t get off because he was frightened to. He saw his life in engineering terms of ‘drifting and spinning’, with no ‘absolute zero’ and he was ‘dragging his anchor’.

He was assisted by services to get a flat on his own in a lovely old building, in the same town, but it was by no means suitable for someone with mobility problems, fresh out of hospital, being on the first floor. His love of driving was put in jeopardy, with his driving licence taken away for two years, which made him dependent on lifts. When it was returned he was restricted to a semi-automatic gearbox and utilised the Motability Scheme, which he found hugely beneficial.

He wanted to get back into a career but it wasn’t easy. A trip to the Job Centre made him really angry. The manager looked at his notes and then the computer screen before declaring, “Well your degree hasn’t done you much good has it!” The man had no comprehension of Christopher’s situation. He began a course using past skills and it was only through the experience of trying this out that his eyes were opened to his own limitations. He began to realise that he wouldn’t be able to pursue what he wanted to. His parietal lobe was affected by the brain injury: previously he’d derived a great deal of pleasure from this, in that it is the area of the brain used for mathematics. Job placements came and went, making him very disillusioned with the system: jobs were promised at the end of placements if he did extra work for no money, which came to nothing, in one case being passed over for a young apprentice. The employers took the money for placements and put him back on the street. He felt used, abused and like a commodity. He realised what the system was all about and did no more work placements.

Christopher realised that he needed to seek what he was: he needed to seek some kind of self-identity on which to hang his hat. He felt that so long as he didn’t have that self-identity his memory wasn’t working properly, as if the self-
identity were the gears for the memory. The problem was that he didn’t venture far at all as he still felt like he was on a roundabout spinning. It was as if he were living an inverse of the life he had previously led. There was nothing he could compare this to or relate to. It led to an immense feeling of loneliness. One day he was watching a film on television called, ‘Awakenings’ by Oliver Sacks. He was intrigued by what he was seeing. He obtained the book from the local library and in the process of reading the book, he found it was the first time he could identify with something: the character named Leonard. Leonard was also doing a PhD and had a brain injury. He made notes about what Leonard was saying and focused on two quotes in particular. One acknowledged the dark and lonely place that they were both in. The other was more optimistic, along the lines of, having been to that dark and lonely place, what else could there be to fear that's worse. This was a revelation to Christopher and contributed to him becoming closer to society and beginning to feel more normal.

Christopher felt that he wanted to close the trap door that he seemed to have fallen through, into an immensely dark place. He began a quest to try and do just that. He was aware others may follow him and fall through the trapdoor and he wanted to close it.

His flat was representative of his head: he hoarded and it was in a bit of a mess! He described himself as a car jacked up on bricks, wheels spinning, not going anywhere or alternatively, on a roundabout going so fast he was afraid to step off. He still needed to seek what he was. It was at this point in his life (about seven years post-injury), that he allowed a friend to get close enough to him, in order to slow the roundabout down, to a point where he could consider stepping off it. He saw that he needed to experience things in life or he’d never know what he was capable of. He told himself that nobody with these types of problems would be better at dealing with them than himself: he had an engineering background, which gave him skills to tackle problems with a degree of strategy and problem solving. He liked researching things and solving puzzles. He had the family trait of diligence and doing one’s best. He found he could conjure up techniques through what other people take for granted. His Dad encouraged him to get out and about before life had passed him by. He was an advocate of the phrase, “use it or lose it” and decided he needed to stay on top of his stroke. He researched Pilates and began a regime of Pilates exercises. He found that he could usually solve a problem by just approaching it
differently and appreciating that it would take him longer. He began to be thankful for the little things in life, gaining joy and appreciation from them, which saw him through the dark patches.

His knowledge of life pre-injury in engineering was a vital resource on which to draw: he was able to analyse his life, strip it down and re-build it, in the right order, using the right process. He knew that appearances could be deceptive. He learnt to play and adjust things to try and get what he wanted. He realised that he would have no more physical repair and he would have to treat himself like a new ‘system’. This was a difficult realisation as he was still grieving for his past life at the time.

A charity was starting up in the town, to try and establish a disabled living centre, which he decided to become involved with. This gave him a social outlet once a week and he took on the unpaid role of running the website. He had hoped that they would offer him the contract to run the website on a more permanent basis and was disappointed when they chose not to do that: he didn’t know if they lacked trust in him or were fearful about placing the responsibility in his hands. Having had that website, which he’d designed, taken away from him, he decided to establish his own.

He’d become interested in photography and the local national park had commissioned him to do some work for them. It was through this link that he began advising them on disabled access: for Christopher to go rambling he would need the use of an off-road wheelchair and the park authority were looking to buy some. This satisfied a need to still be involved in electro-mechanics, through the specialist vehicle, as well as contributing to making the national park accessible to people with mobility issues. It also meant that he was maintaining links for possible future commissioned work and so was very happy to be involved.

In social encounters Christopher felt the need to declare his disability, in terms of his head injury, which is not obvious through conversation. Another disabled person once criticised this, after introducing himself as a disabled person. The man said he wanted to know about Christopher and not his disability. This was the first time he was aware that he was in the habit of doing this. He became aware that he did this so as to take some of the pressure off a potentially
awkward social situation, by explaining before a judgment is made about him because he doesn’t meet someone’s usual expectation in a social situation. He was aware that there was much ignorance in society about brain injury. Also, he found motorists had no consideration for disabled people when it came to parking in bays for disabled people. He felt quite happy to challenge people if they parked there without entitlement, feeling like an advocate for people with disabilities. In general he thought society needed to be more open minded to disability issues, of all sorts.

A significant factor in initiating Christopher to move forward in life has been finding a girlfriend, Angie. They share common interests and have similar taste. Angie gave Christopher something much more valuable than money, much more valuable to him than anything else: time. Consequently he gives her time back and they operate like a team. She has a physical disability herself, which she’s had from birth. He sees her experience as giving a different perspective on life, growing up having had to fight for things: whereas with an acquired disability like his own, he had to overcome everything being taken away, before finding his way again. But she helped him do this and has taught him a lot about life. He’s not sure she fully grasps the extent of his brain limitations but she helps with these and is someone to turn to. All in all meeting Angie, and making the move to a bungalow in a village to be more independent, was the start of ‘seeing light at the end of the tunnel’ for Christopher. It had taken 17 years post-injury to think like this and reach this psychological milestone. He still needs periods of peace and quiet to cope with his brain injury. The quietness of the village gives him clarity of thought and he is able to better plan and think because of it. He’s more reliant on his car now he lives in a village, for fetching and carrying and accessing shops, as there are no services in the village.

Some years ago Christopher had tried to windsurf again, to no avail, as he couldn’t get back on to the board if he fell off. He tried land yachting, but wasn’t allowed to take it to a competitive level, as he required assistance to get going. He missed activities that gave him an adrenaline rush. Many of the sports he looked at didn’t have the infrastructure to support competition for disabled people, until he looked at sailing and ‘Sailability’ for disabled people who wanted to compete. Angie was the catalyst to engage him in this and said, “Come on, let’s go” and they liked what they saw, became involved and hope to take it to a national competitive level. Finances are limiting when income is restricted to
benefits, so they aren’t able to afford their own boat and ideally would like sponsorship and are considering ways this might be done in the future. The practicalities are complex: once finding out about the venue of competitions they have to source the boat hire and the accommodation with disabled access. Some of the people they meet in the competitions are quite inspirational, it’s exciting to compete and something they really want to be part of. It's also a serious playing field for competition they can engage with, rather than a disability 'sideshow' in other sports.

Frustration in completing physical tasks has been an issue for Christopher over the years. An engineering trait is to be practical and the use of one hand limits Christopher this way, especially when trying repairs at home. He has been adapting a recumbent trike that he bought to use for cycling. He recently joined in a planned bike ride with a local cycling club. The club members are willing to accommodate him and it allows him to engage in the social aspect of cycling as well as the rehabilitative aspect of physical activity. He still does daily Pilates exercises recognising the link between physical activity, a healthy immune system and good mental health. The alternative way he participates with his recumbent trike gets him to consider the alternative dynamics, from the engineering point of view.

The outdoor activities like the sailing, cycling and rambling give Christopher material to populate his website. This website is not just for people with brain injuries, but a resource for any disabled person. It is an opportunity for him to share the wealth of experience and knowledge he has accumulated in the 23 years since having his injury. It is for disabled people to share first hand experience and knowledge to aid those new to disability or in similar situations: to stop them falling through the trapdoor. He began building websites with no experience of this and had to engage in a great deal of problem solving in order to be successful at it and learnt a lot along the way. Looking back, he wonders how he came across with the original website for the charity and why they chose not to give the contract to him. Of course hosting a website means that he needs material to update it, so the outdoor activities go some way in fulfilling this function. Publicity and promotion are areas that he needs to develop and has tried various methods to date, such business cards and wearing T-shirts at the Motability show.
Christopher has continued with his charity involvement and took the responsibility as chair of one charity and committee member for a new branch of Headway. His preferred way of the charities operating is to be proactive rather than complacent and comfortable. Ways of increasing revenue is a current concern, as is publicity. The charity involvement has led to other activities too. He has done some auditing for the NHS and this led him to undertake a leadership course to assist with this. He found that the course allowed the participants to blossom and made him realise his limitations in terms of public speaking about his personal situation: he needs to be aware of becoming emotionally overwhelmed.

The benefits system is a continued source of frustration for Christopher, especially recently with regard to cuts and the bedroom tax. He feels everyone wants to put a hand in the disabled person’s pocket these days. It makes him feel like a conduit or being traded like cards, being given money at source and then someone further down the line taking it away again.

These days he is still prone to falling and is beginning to think it may be linked to his eyesight and co-ordination, as well as low blood sugar when tiring. He doesn’t realise it’s happening until he begins to fall and then feels like a passenger in the event, unable to stop. One particular time he fell crushing Angie’s Christmas tree, which wasn’t well-received. He manages independently in his bungalow, apart from his laundry, with a few hours of care support each week.

The website has the potential to become part of the ‘neuro-culture’ that wasn’t there for him when he had his injury and has gone partway to fulfilling his quest of closing the trapdoor. It is contrast to the public perception of disabled people being looked at as being ‘useless’ and allows him to be taken seriously again. He has learnt to be in control of his own destiny again, rather than someone else being in control. He has begun to feel some of the pride in life he’d lost and he has begun to move to a point of seeing his life as being more than looking for replacements for the old life he’d lost and this new life has value and he no longer feels inferior. Now he feels like a man of substance and even though he’s a poor as a church mouse he feels rich in so many other ways. He views brain injury as a mammoth thing and views his experience as one of two lives, before and after brain injury. Looking back to his first life, he could have seen himself
coming out of university, achieving and possibly becoming a capitalist and that
doesn’t interest him anymore. Now he’s more intent on becoming a catalyst.
Appendix R: Narrative analysis

Participant 10 – Elizabeth’s story

Elizabeth is in her fifties and has been married to Trevor for twenty years. They live in a remote part of the north of England, in a house shared with their teenage son and daughter and Elizabeth’s mother. They are a strong family unit. Elizabeth originally met Trevor when they were both helping out a local swimming club for people with disabilities.

She grew up with her mother and father on the outskirts of a large city, in quite an affluent area, though moving several times. This necessitated Elizabeth to reform friendship groups a number of times and school carried with it a host of difficult memories. She made friends each time she moved but academically, she struggled with mathematics and felt ridiculed by the teachers because of this. One particularly stern teacher liked to make the class stand until they each answered a mathematics question correctly and each time Elizabeth found herself last child standing in humiliation. With the impact of this experience etched in her mind, Elizabeth decided to try a future career involving helping children herself. She thought that she may be able to prevent some child from having to go through the same humiliation she experienced and on leaving school went to college to train as a nursery nurse.

When she qualified it was difficult to secure regular work in a nursery. She tried other work in the meantime but still wanted to be a nursery nurse and so eventually decided that she’d bite the bullet and open her own nursery. Her parents helped her out financially to purchase a property in poor repair. She had it renovated and lived above the premises. This brought with it success and she took on staff to help her run it. After a few years competition moved in to the area and the business began to run at a loss. She’d enjoyed her time as her own boss, enjoyed the freedom and decision making, but perhaps the time had come to sell up. This she did and managed to find employment in a state school nursery instead. Despite eventually running at a loss the business venture had been a success in so far as the investment in the property allowed her to go on to buy a small house in a popular local town, from which she could walk to work.
Around this time her father developed Parkinson’s and became increasingly disabled. Her mother took him to a local swimming club for disabled people and one night they persuaded Elizabeth to go along with them to help out. It was here that she met Trevor, who was also a helper. They soon became friends and then began dating. Trevor had experienced a traumatic brain injury in a climbing accident in his late teens some years earlier, but this didn’t bother Elizabeth. She liked him for who he was and saw his memory problems and epilepsy as part of him. She knew from the beginning that they were right for each other and it wasn’t long before they were married. Trevor talked about his accident but it didn’t affect their marriage.

Trevor had been to acting school in the south of England and still had the majority of his work in acting roles around the country. However, it became apparent that his poor memory was making it increasingly difficult to learn his lines and his acting parts became fewer and fewer. He had had small parts in high profile television dramas but the offers dried up. He tried other work, but was disadvantaged by fatigue, as a symptom of his brain injury. Fewer jobs were available in the local area and traveling time on top of work meant that it was difficult to hold down work. Elizabeth continued to work at the school, but her role was changing to becoming a special-needs assistant and moving up with children through the school, with one to one support. It seemed to make sense for Trevor to be a househusband, especially after their son George was born, which is the routine that they settled in to. However, when Charlotte was born Elizabeth decided that she’d had enough of working full time outside of the home and she reduced her hours to part-time, wanting to see her children grow up.

Trevor had a facial disfigurement as a result of the brain injury that didn’t affect Elizabeth but made Trevor very self-conscious, despite her reassurances. One day they came across a news article about a new procedure that involved a nerve transplant, utilising a muscle from another part of the body to potentially remedy this. They began to research this further and eventually Trevor’s surgeon agreed to undertake the operation. Unfortunately this was not the success he had hoped for and his facial disfigurement remained. This had an impact on Trevor as it was noticeable to other people.
The expanding family necessitated a house move to another rural town where accommodation was cheaper. They bought a nice property near the railway line and settled into life here. As time went by the relationship with one of their neighbours deteriorated considerably over an access dispute. They came home one day to find the block paving upended in their path and their car suffered damage at considerable expense. As Elizabeth’s mother was now widowed and living alone the family decided to sell both houses and move to a large property in the countryside to run a bed and breakfast business. Their house sold easily but surprisingly their mother’s didn’t, even though it was of significant local interest and in a lovely location. They lost the property they were interested in and moved in with Elizabeth’s mother. The house was large enough to accommodate two families, living separately but with connecting doors. This took some getting used to on Trevor’s part, especially as he’d lost his driving licence due to epilepsy and the remote location meant he was reliant on his mother-in-law for lifts or had to walk some distance to catch a bus or train. Nighttime epilepsy had become a continued feature of their lives, even with persistent changes of medication to try and reduce it. Elizabeth coped by being a light sleeper and guiding Trevor back to bed when she needed to. The children were unaware of their father’s nighttime wandering and Elizabeth took it in her stride and saw it as part of her role, being married to Trevor. Elizabeth found that she was having to be the main family driver and at times Trevor became quite frustrated. There was a period when he had considerable mood swings, prompted by his being unable to drive or hold down work. Depression was also a feature of his brain injury. Elizabeth was patient and understanding throughout and empathised with his plight, recognising that he must have a lot to cope with and that he did very well, taking everything in to account. At times his frustration came out as violence but only ever to inanimate objects such as hitting out at the wall or doorpost. He was always remorseful once the episode had finished. They sought professional help and Trevor began to use coping techniques such as withdrawing from situations when he felt the anger coming on.

Elizabeth had always enjoyed working for herself and she became interested in selling magnetic bracelets at country shows. She was also a keen knitter and spent hours with her knitting machine making jumpers and hats to sell on the stall, as well as homemade cards. She would take herself off upstairs and lose herself in the flow of knitting or card making. Trevor was less keen on the selling
but enjoyed accompanying Elizabeth to the shows and meeting people and he would chat to customers as they visited the stall. They’d been introduced to the magnetic bracelets in the south of England where they seemed to sell well, but found that the market for them was less in the north and eventually the business dwindled.

Family holidays took the form of caravanning around the UK, travelling considerable distances. This gave a sense of freedom and enjoyment to Elizabeth and she much preferred the flexibility of sleeping in their own caravan to a regimen of a bed and breakfast holiday. It wasn’t always easy, due to Trevor’s nighttime epilepsy, but they assumed there was no problem here as they never received a complaint about disturbing the campsite at night. Travelling the UK with the caravan gave them the opportunity to support the National Trust and they developed an interest in visiting historical properties with their membership. They also took advantage of using their membership locally in the beautiful countryside.

Elizabeth enjoys the pleasures of watching the wildlife from their rural home. The calming environment is preferable to coping with unpleasant neighbours in the local town. Some unusual birds nest nearby and she looks out for them in flight and animal footprints. She currently has her teenage children at home and her mother and fiercely considers the future with all of her family in one large house, including Trevor’s parents, should they become infirm. She remembers the past with sadness, at her father not being able to be looked after at home before he died. Being surrounded by family brings happiness to Elizabeth and she enjoys the cosiness of the family living room with the log burner at it core.

Over twenty five years later Elizabeth remains working at the same school she entered after giving up her own nursery business. She misses the freedom and opportunities of being self-employed. The nature of the work has changed as the years have progressed. She began in the nursery and now works with all ages of children with behavioural problems, which has a stressful dimension to it. She has thought about this and doesn’t know if the children are more challenging or if she is less able to cope as she has got older. She has a plan to become self-employed and work with Trevor as they work well together. Recently they have begun to be network marketers, selling and distributing cleaning products in the local villages. Elizabeth finds the prospect of this
venture exciting. Currently Trevor is doing most of the work and its flexibility suits his talents and symptoms of the brain injury, such as fatigue and memory problems. They have developed a method of colour coding the goods and making careful notes of what needs doing and who has been contacted. Elizabeth sees this form of self-employment as more sustainable, with the networking community encouraging and guiding. They sometimes felt as though they were floundering with the magnetic bracelet business as they were totally independent. The business has had a positive impact on Trevor, knowing that he is working again and it has helped his mental health issues considerably. The whole situation makes Elizabeth happy in this work, family and her marriage.

The rural location brings the benefit of no difficult neighbours and a calming environment but at times it has been difficult for Trevor when he has had his driving licence taken away, which has occurred at times. If his epileptic seizures occurred early evening it was not technically considered as nighttime and made a difference to the rules on driving. Buses pass on the main road which is seen from the house but a considerable walk away, as is the nearest train station. Elizabeth is at work part-time during the day so negotiating the driving requirements within the family has been time-consuming for her. At times she thinks she has no spare time to herself, but this has not impacted on her being happy and content within her small family unit.

She has got to know the villagers through attending the local Women’s Institute. Initially Elizabeth went along to accompany her mother after her father died, but she continued to be involved and takes her turn being hostess and attending talks. It has actually opened up the network marketing and some of the members are now also her clients. Other than that Elizabeth is busy with little time for other friends. She considers friends to be important and has two friends in particular she either meets or writes to a few times a year.

The household duties are shared though Elizabeth tends to do more than half. Sometimes this is for ease as Trevor’s memory problems can create more work: he doesn’t remember where he puts things and familiar objects can end up in unfamiliar cupboards. He has some household duties that he enjoys doing himself, such as loading the dishwasher after a family meal, spending time alone, listening to the radio.
Elizabeth’s entrepreneurial spirit is at the heart of her future aspirations with her family. Charlotte is a keen baker and although currently in an apprenticeship Elizabeth hopes to open a bakery with Charlotte one day, combining it with a dream of Elizabeth’s to open a café. The network marketing could link with these new businesses and Elizabeth may be able to become totally self-employed again.

Elizabeth is quite clear that her marriage is a happy partnership and by no shape of form does she see herself as Trevor’s carer. Yes, she acknowledges that he needs a form of care if his nighttime epilepsy occurs, but this is the type of care she would administer to anyone in terms of being caring. She is keen to stress that she is a wife and not a carer. She looks back at the times when her father was very disabled and her mother became his carer and sees this as quite different. As the future holds no certainties it may be that Trevor becomes Elizabeth’s carer in the future. Elizabeth assesses her situation as being a very lucky person. She is happily married and has a teenage son and daughter that enjoy spending time with their parents. She looks forward to the exciting prospect of the new self-employment venture.
Appendix R: Narrative analysis

Participant 11 – Diana’s story

Diana is a woman in her seventies who lives alone in a small rural village in the north of England. She brought her four children up here, is involved in village life and has lots of friends and a close family. Diana’s story begins with the birth of her four children from the 1950s onwards. She became mother to a son and a daughter quite soon after one another, only to find her widowed a few years later. She married again, this time to an older man who hadn’t been married before. He was a good father to her two children, though quite strict. Diana described him as a businessman. Similarly in this marriage she had two children, a daughter followed by a son. With four children, the youngest of whom was six weeks old, she found herself widowed yet again. This youngest son was Gordon and although he was never favoured above the others Diana always thought to give him special attention as he had lost his father so young. Gordon stood out as being a very, very loving son who took after Diana in her love for nature.

Diana’s primary role in life was to be a good mother to her four children. All she ever wanted was for her children to be brought up in a nice manner and for them to make the best they could out of life. She wanted them to have the best education but the school years had their ups and downs for the children and they weren’t all academic. Her older son took an apprenticeship: the older daughter went to college, whilst the younger daughter took longer to find her way in a career but caught the others up eventually. Gordon had a love for the countryside and animals and moved on to agricultural college with an interest to work with poultry. He was considered to be a good worker and was in demand when he left college and settled into a job nearby. As it happened he was headhunted with little experience to be manager of a large poultry farm. He was daunted at the prospect of this and refused initially but the farm owner was persistent and persuaded him with the lure of a handsome salary. Diana was reluctant at a young person taking on so much responsibility. She knew that had Gordon’s father been alive he would have recommended him gaining more experience before taking such a bold step. However Gordon took this on aged 22.
Diana had a keen interest in gardening but was struggling to manage the upkeep of a large garden in the old family home. She decided to move to a bungalow in the same village where it was much easier to tend to the garden, now living alone. In hindsight she believes she should have heeded the superstition of not moving home on a Friday: she moved in to the bungalow only to receive a phone call that night that Gordon had had a serious road traffic accident. Living in a rural community comes with narrow country roads and a young man with a responsibility to finish jobs and a liking for cars and fast driving led to Gordon colliding with a combine harvester.

The family gathered at the hospital waiting for news and was told that Gordon had a fifty – fifty chance of survival. Diana’s reaction was to flee from the hospital due to the trauma of it all. However, he did survive and underwent a prolonged hospital stay to undertake rehabilitation. Diana and Gordon were not happy with some of the treatment Gordon received in hospital and had reservations about cleanliness and the care and attention to Gordon’s individual needs: he rapidly lost weight and the family took time to consider what foods he may be tempted with, purchased them and asked hospital staff if he could be given them, only to find their wishes ignored. She observed conflicting interventions between the care in the two hospitals that had responsibility for him but prefers not to be too critical now time has moved on.

Eventually Gordon was discharged home. Diana was keen to encourage his independence and they found a flat for him in the local village where the family lived. Rehabilitation continued at this time but it appeared to lack an impact and Diana considered the health workers to be lacking in a strict or timely approach with Gordon, all except one older woman who seemed more willing to take an individualised, firmer approach and encouraged the family to fight for compensation to support Gordon. Diana thought that her older son could have been more helpful to them at this time, with advice that would have helped them. She was happy to put her home forward as collateral for the legal costs, as was one of her daughters but Gordon prevented them going ahead with this incase they lost their homes. The legal action was unsuccessful. In rehabilitation Gordon was pushed towards work sooner than he was ready and it failed. It was at this time that he began collecting rubbish in the village and hoarding it in his flat. Diana would have liked the health workers to take a stronger approach with
Gordon over this, but the client-centred approach was in conflict with this: the behaviour continued, resulting in him being evicted. They managed to find Gordon another flat, but it was on the proviso that Diana acted as guarantor that Gordon did not collect rubbish to the same extent that he had been. There have been other attempts at vocational rehabilitation but being protective of Gordon, Diana was critical that he could be taken advantage of on the work placements and stepped in to question this in the past, even though today she thinks she perhaps ought not to have done this.

Diana sees fatigue is a large inhibiting factor in Gordon’s life and prevents him from holding down full time employment. It has got to the stage now where Gordon wouldn’t want a job if he were offered one, unless it was on his own terms. He has taken a number of temporary positions but each time they finish he has a complicated procedure to go through to reclaim his housing benefit, which makes life difficult for him. His inability to work under normal circumstances, with an invisible disability, can cause conflict with people who don’t understand his personal circumstances. Diana has a very difficult neighbour with whom she has been in conflict for some years. When he sees Gordon helping his mother with jobs, such as pushing a wheelbarrow, he interprets this as Gordon being able to work and shouts abuse about him being a “benefit cheat” with threats of reporting him to the authorities, taking photographs. Diana has been so upset about her neighbour’s continued malicious behaviour that it has driven her to seek legal advice about dealing with him, but there is nothing she can do but ignore him. This breakdown in the relationship with her neighbour sets her on edge every time she sees him and avoids spending too much time in her front garden in case it involves coming in to contact with him. This conflict with her neighbour intensely brings out her protective maternal instincts, that she describes as animal-like, being so intense.

A number of other healthcare workers have been ineffectual and not always working towards Gordon’s precise needs in the past. He had a good knowledge of gym-work and keeping fit and Diana encouraged him to visit the gym as an interest. However, his paid carer rubbished this idea and discouraged it, principally because she didn’t like waiting for him at the gym. A young male worker was much more appropriate and Gordon responded very well to him, but services seem limited and sort-lived and this intervention came to an end. Originally the family members were told that most progress would happen with
Gordon in the first five years post-injury but Diana has continued to observe progress, sixteen years later.

Diana was puzzled as to why the professionals couldn't give an explanation of why Gordon felt the urge to collect rubbish. Nobody seemed to give them any answers, which she expected. Gordon had at times regularly expressed suicidal ideation and Diana lived in constant worry that one day he would take himself off to some local woodland and carry this out. Gordon's sleep pattern was disturbed and it was during one of these periods, when he was watching television during the night that they began to get an understanding of his irrational behaviour. He watched a programme about a famous boxer with a head injury and his subsequent depression and behaviour and they took this to the head injury services, demanding to see a psychiatrist for assistance. Diana's second daughter was a businesswoman and used to tackling difficult situations and stepped in more forcefully until their demands were acknowledged. The result was transformational: Gordon was prescribed Prozac and his mood improved significantly and the collecting behaviour modified but not quashed. Once on medication he gathered an awareness of his behaviour that he didn't previously have and circumstances improved somewhat. Diana came to a conclusion about the collecting behaviour herself, which she believes to this day. Here was a young man with a promising future ahead of him, struck down in a car accident, only to lose everything: the collecting was psychologically his way of trying to retrieve some of his lost life. He remains temperamental to an extent today, sometimes having irrational arguments and shouting, but Diana firmly believes that it stems from frustration at not being able to live life, as he would like. She finds it distressing when people judge her son as being angry and aggressive without trying to understand his circumstances. He has been known to take himself off and not respond to the family's phone calls in the past, which can leave Diana distraught and concerned due his past suicidal ideation and increased risk of harm due to his visual impairment. She reprimands him when he does this and makes it clear that she expects him to let her know where he is, out of her maternal concern for him.

Diana is grateful to one of Gordon's friends who lets him stay over in the local town once a week so as he can attend a support group run by the local head injury charity. She is full of gratitude for his friend taking an interest and being patient with Gordon and hopes this friendship continues. If he didn't have this
opportunity he wouldn’t be able to attend due to the infrequent bus service to their village. Diana and her daughter thoroughly enjoy the annual adventure weekend organised by the charity and although Diana doesn’t take part in many of the activities due to her age, she is full of admiration for the genuineness of the people who attend. She sees a quality in people with head injuries that is often missing from the general population, in that they have a realisation of the really important issues in life and are accepting of one another. She regrets Gordon not maintaining friendships with his school and college friends, but Gordon rejected their attempts to maintain links long ago. He thought they no longer had common interests, with them marrying and having families and careers, which he did not.

Diana views the Gordon before her today as a different person from the Gordon she knew before the accident. Before the accident he had a terrific personality. Yes, he was young and would have matured, (it is sixteen years since his accident), but his maturity seems to have regressed and he is almost childlike in some situations. This is displayed mostly in social interactions between Gordon and others. He often seeks attention and sometimes speaks in a childish manner, which Diana thinks draws attention to his difference and she would prefer that he behave as normal. He appears normal in social situations otherwise. It is situations like this that she is torn between reprimanding Gordon and letting him continue to appear as different from the social group. Usually this is managed but it becomes more difficult if he has alcohol and he is disinhibited. She notices the reaction of people around them and feels uncomfortable but Gordon doesn’t pick up on the cues. She prefers not to dwell on the difficulties and opportunities lost over the years, as the pain is too great: she sees looking forward as more important. Subsequently, when she meets other people who have had a brain injury she considers it proper not to talk about the circumstances leading to the trauma unless the person offers this. She is a firm believer in positive thinking and praises her son for how he is today.

Diana has always had a love of nature, which she shares with Gordon. One of her main hobbies is gardening, which she does around her bungalow. She sees this as an inherited family trait in that her father and his father before him all liked to garden and it is something that she’s passed on to her children, now that they are adults. She is predominantly a fair weather garden and as soon as the spring flowers start to come through she begins spending time getting the
garden ready for the year. Her garden is well established now though she sometimes rearranges parts of it and involves Gordon in doing this. Gordon doesn’t seem to enjoy gardening like she does, possibly down to the impaired vision that was a result of this brain injury. But he is helpful in doing the hard work such as digging and he willingly does this for his mother, although she does have to supervise him to do this properly. Diana thinks that the brain injury has taken away his ability to take action independently. Diana sees Gordon as good company.

Her gardening hobby becomes a focus for presents from her family for birthdays and Mothers’ Day and the family often give her gardening vouchers which she spends on trips to the local garden centre with her youngest daughter. Some of her plants hold great sentimental value, like a succulent that came from a cutting from an old family doctor many years ago, which she swapped for one of her plants. Her love of flowers is known to relatives and sometimes they send flower arrangements which she'll maintain with refreshing and rearranging the flowers, but otherwise she believes it is best practice to leave flowers naturally to enjoy them for longer.

The village has a number of weekly activities that Diana is involved in, such as coffee mornings and a craft club. She has been a long-term member of these groups and attends regularly. These activities keep her so busy she sometimes thinks she would prefer to have time to herself in the home, but she continues to go. When she is at home by herself she is a keen knitter and enjoys needlepoint. She has been a knitter since a small child and knits jumpers to wear when she’s at home, or for the family. Many are the time when she has no reason to knit so she will knit squares for charity blankets. Knitting is something she does to pass the time and relax rather than for the end product. In contrast the tapestry and cross stitch she has completed over the years take more care and attention and she has had these made in to pictures and cushions displayed around the home of which she is proud. The tapestries are a hobby she enjoys more in the winter and she usually carries over the theme of flowers in this work too.

The village setting has its bonuses and drawbacks for Gordon living with his brain injury as far as Diana is concerned. The older people tend to be accepting and understanding of him and his behaviour but the younger people tend not to
be. She puts this down to their lack of knowledge about brain injury. She would like them to accept that Gordon has had a brain injury and that that is the way he is, distinguishing this from him being seen as different and excluded. On the positive side of village life she acknowledges that he may be vulnerable if he lived in a big city and someone she has met through the head injury charity has experienced abuse and violent attacks with city life. If Gordon lived in the local town, however, he may have access to more specialist services, such as being involved in gardening schemes. He isn’t able to access this type of activity as the bus service is infrequent in the village where they live and a car is necessary to access such as work and shops. Diana relies on taxis, which are very expensive, combined with family lifts, for shopping and such as the dentist as she doesn’t drive herself.

Gordon’s main love of life was driving, which of course led to his accident. He was so grateful that he didn’t injure anyone else when he had his car crash and only himself. The police at the time made a comment about possibly prosecuting Gordon for his driving on the day of the accident and inferred he may have incurred penalty points on his licence and a driving ban but they weren’t pursuing this. Diana saw irony in this comment as in her eyes Gordon had been awarded a life sentence with his brain injury, although she does think he has improved tremendously since the early days. However, she is thankful that he has never attempted to break the law and drive since his accident and commends him for resisting this.

Diana and Gordon spend a significant amount of time together. They laugh together and she sees it as important to show him that he is loved, as he has no life partner to give him affection. She worries about this for the future when she dies, as at the moment she is the centre of his life and has always been there for him. Gordon is good company for Diana and he is able to tackle jobs around the home that usually a man would carry out, visual impairment allowing.

Diana has no faith in God as a result of how life has turned out for her son. She would have expected a god to be protective if there was such a thing and is disillusioned as a result. She thinks back to the worry she had when she was pregnant, wondering if her baby would be alright and how she would accept circumstances if it wasn’t. She compares this to Gordon’s brain injury which was thrust upon her suddenly, with no time to think about it and her approach has
just been to ‘get on with it’, but she views it as something she hopes would
never happen to anyone. This is paradoxical to the genuine positive qualities
she finds in people with brain injuries, which she thinks is a result of them
having an acknowledgement of the important things in life now that they have
undergone a serious life-changing experience. She would like people to be
aware and realise these positive characteristics that many other people lack.
Appendix R: Narrative analysis

Participant 12 - Rita’s story

Rita was born in Africa in the 1970s. As a child she lived with an aunt, her mother’s sister and saw little of her nuclear family. At quite a young age she was sent to be educated at a Catholic boarding school. Daily life at the school was centred around religion, which was to be the beginning of a large influence on her life. She didn’t grow up with her family but grew up with God and grew to love him. Although Rita enjoyed the spirituality aspect of a religious boarding school she found the intensity of prayer throughout the day somewhat overwhelming. By the time she was thirteen she had grown weary of the approach in the school and she made the decision to become a Seventh Day Adventist, Born Again Christian. This approach to religion suited her much better and it was around this church that she built her life, as a teenager and on leaving school. A feature of the church was attending crusades across the country, which she did frequently. She soon found that she excelled in her singing on the crusades, to the point that she became well known for this within the church in her country. She continued to progress with her studies and she moved through high school and college, to study primary education at university. Her interest in primary education extended to children with special needs and it was teaching such children that became the focus of her career.

Her developing spirituality over the years led her to marry a man who was also spiritual and together they were be heavily involved in the church. They became involved in a church project in rural Africa, distributing items to farmers, whilst at the same time Rita taught in the local schools. They had four children together but as the years passed, their relationship deteriorated and she began to look for a way out of the situation. The only option open to her was to engage with further study, overseas. She thought that if the whole family could have a new start overseas perhaps her husband’s behaviour would change and they could become a happy family unit. However, that was not to be.

Rita was delighted to be accepted onto a scholarship programme to study in the UK. Coming to the UK was a huge step for her as it was not an option that many people from her country took. She chose to focus her studies again on special
needs education and the family relocated. Whilst she settled easily into UK city life her husband did not. This was compounded by the fact that he was asked to leave three different jobs and found the UK cold compared with his native Africa. He spent a lot of time on the telephone to Africa. Rita had completed her studies and began work. She and her husband decided to separate. This caused a legal complication for the family as he no longer had UK residency status if they divorced. Rita was awarded custody of the children, as the mother and wage earner but unsurprisingly her husband was not happy with this arrangement. He refused to leave the country without the children. A legal battle ensued and Rita became weary of the struggle for custody. Her lawyer advised her that the easiest way to resolve the situation was for to allow her husband custody and then he would return to Africa with the children, which she agreed to.

Now Rita was living alone in the UK. She found city life lent her an air of spirituality due its peacefulness. Daily life in Africa tends to be conducted outside of the home with hustle and bustle whereas here, possibly due to a different climate, people spend more time inside and this appealed to Rita. Her work was in the social care industry and she found people supportive of each other in the city community. After a few years of living alone she decided that she would like to have someone else in her life. However, she didn’t have many opportunities to meet a potential partner and she was rather scared by the thought of internet dating. One day she was talking to a work colleague, who was involved with her in supporting an elderly woman with her care. She asked Rita if she would like introducing to a man she knew who lived some distance away in a small rural town. Rita agreed and she learnt that the man was called Peter. Her colleague phoned Peter immediately and told Peter that she had found him a wife!

Rita and Peter began getting to know each other over the telephone, due to the geographical distance between them. Peter said that he would like it if he only phoned her and Rita liked this idea; she thought he was being romantic and wanted to save her money from paying for the phone calls. The relationship continued for some months this way. Peter would ring and ask Rita, “Will you care for me?” Rita was a little dubious as to what he meant by this but chose to interpret this as a romantic gesture and was touched by the comments. Eventually they arranged to meet by way of her travelling over to have a holiday with him in his home.
She travelled by coach and Peter was there to meet her with his dog. He took her back to his house in his car and he settled her in with a drink and some food. Quite suddenly Peter went down on one knee and said to Rita, “Will you marry me?” Rita was taken by surprise but felt that she needed to give him an answer quickly. She found him a very handsome man, she liked his communication style and importantly, she trusted him. She agreed. Peter suggested them marrying in a short period of time which Rita was happy with. They visited the local church and set a date for eight weeks later. Peter sought permission from Rita’s aunt and uncle in Africa, which they gave. Rita invited her friends from around the UK and the day came and went successfully. It’s at this point Rita’s life changes.

Rita began to notice some unusual patterns in her new husband’s behaviour. Every morning he would like to boil several eggs, the same number of eggs at the same time and then eat them. The house had no other signs of cooking utensils and pots and he never cooked any other food in the house and tried to persuade Rita that they eat in a local hotel. He’d been living for some years in this sheltered accommodation that they now shared yet it was clear to Rita that he hadn’t been receiving much support. The house was very dirty (to the extent that visitors refused to sit down) and Rita set about cleaning it. The bed sheets were ragged and unwashed. She scrubbed the house and visited charity shops to buy new sheets. Her husband went out at the same time every morning to run the same errands. When they were out in the local town Peter would point out people who were family members, including a daughter and two sons, yet they did not speak to their father when they passed by. This puzzled Rita at first and then she began to put things together to see that there was some sort of problem apparent.

Her husband couldn’t bear any noise in the home and he forbade her to clean when he was present. She had to wait until he went out each morning. This was even to the extent of him not being able to stand the noise of plates being washed or put on the worktop. He would become frustrated and angry if this happened and she quickly learnt not to aggravate him. She learnt not to talk to him in the mornings, again because of his dislike of noise. His routine was very fixed and he suggested that they always go to bed at eight-thirty in the evening. This was a disappointment to Rita as it meant that she couldn’t watch television,
even if there was a programme she wished to see. Any time spent watching television had to be done with subtitles and no noise, again because Peter couldn’t bear the noise. They could no longer attend church as Peter left to visit the toilet several times during each service. Their physical relationship was also part of a fixed routine and always initiated by Peter and Rita seemed unable to change this. Unusually, the walls of the house were covered in framed pictures, to the extent that they almost obscured the wallpaper. Some of them were pictures of such as his parents or local events, but some were of naked women, which she found surprising. She also found that he was speaking to other women on the telephone, which she found wholly inappropriate. One day she questioned him as to whether or not they knew he was married. He replied that they didn’t and she asked him to inform them. He did and he stopped this behaviour immediately. Rita thought that he almost didn’t know what was an appropriate boundary with woman.

Then one day he told her about his past marriages and their demise, which at this point Rita held no surprise for her and it possibly explained why his family members were estranged. He told her about a time in his life when he was very ill; it was when he was in his twenties, some forty years ago, when he was hospitalised due to inflammation of the brain and he almost lost his life. His life had changed from that moment onwards. He mentioned the word, ‘encephalitis’ which Rita began to research on the internet. She saw details of possible symptoms and her situation began to make sense at last, even the issue of boundaries with women. Now, instead of continuing to worry about the situation and questioning what was happening she could look for solutions. The first step she took was to contact the Encephalitis Society and they also linked her the brain injury charity, Headway. She obtained their factsheets and books and immediately related to the detailed symptoms and began to see how she could potentially cope with the situation. She also realised that it was not a romantic marriage she had been in all along and she now understood why Peter had asked if she would care for him. She had given her word that she would care for him so she made the decision to stay and work out how to cope rather than leave, which previous wives had done. Now she no longer viewed the situation as a romance but more akin to being in a special needs school (as in her professional training) and learning about how to live with Peter successfully. She loved Peter and symptoms aside he was such a nice person. She
formulated a way of coping psychologically by separating the symptoms from
the man and instead of letting the symptoms challenge their relationship she
was going to challenge the symptoms, similarly to how she worked with special
needs children in the past. This was not an easy step but is the one that she is
still living with today. She was sure that both of them required help in dealing
with the situation.

The first symptom to tackle was around issues of communication. She became
to understand that when he shouted it was through frustration and because he
was failing to understand something. They agreed that if she wanted to tell him
something in the mornings he was happy for her to write it down and they began
using notes. At other times he could only cope with small amounts of
information. Rita began to feel good about these changes when they were
successful. However, it did feel as though she was a manager in a school rather
than a wife. She began to understand why he couldn’t bear any noise and was
more careful with her routine in trying to go along with this.

Rita began to question why Peter had been left to suffer for so long in the
community, especially when he had obviously had plenty of contact with social
services, living in local authority sheltered accommodation. She felt very sad
about this situation. Now she understood about Peter’s encephalitis and his
acquired brain injury as a result of this so many years ago, she began to try and
involve the statutory services. This presented a challenge in itself. Little
progress was made with her husband’s GP. Rita was convinced he had little
understanding of brain injury; being a small community he rarely came across
the signs and symptoms and could do little to help. Rita ordered additional
copies of the charity factsheets and sent them to him. Five different social
workers came to the house and again, they failed to understand Peter’s
problems. She offered explanations about Peter’s obsessional routines but
these were dismissed. One social worker stated that this type of behaviour was
typical of men in this rural community rather than symptoms of an illness. Rita,
having care qualifications herself, challenged this by asking what theoretical
base they were drawing from to explain this and she suspected that if that is
correct there must be many people in the community suffering like Peter and
her! Again, she supplied them with factsheets. They asked if she needed an
advocate, which Rita found amusing as she saw herself as her own advocate,
with her skills and training.
Two and a half years on some progress had been made but life is still difficult. In order to make a happy marriage Rita has taken the approach of living with Peter’s routines that she sees as never changing. Mornings are quiet and they communicate by notes. He leaves the house for an hour, which she uses to clean the house. In the afternoon they have a quiet period of sitting together reading. Peter likes to read copious amounts of books yet Rita queries how much information he retains. Rita doesn’t enjoy this period of reading, but does it as an activity to accompany Peter. They then watch a number of quiz programmes together on television, the same ones each weekday. Peter reads the subtitles but now Rita has some earphones so as she can hear the sound. These were provided by the occupational therapist from social services, who is putting a number of services in place; plans are being made for a move to a specially adapted property that takes into consideration Peter’s dislike of noise whilst Rita is carrying out daily living tasks. Also equipment is being ordered to assist Peter bathing and continual visits to the toilet during the night, plus the new property will have some separate space for Rita. Rita goes along with Peter’s request to go to bed at eight-thirty each evening, but she listens to music or church services on the internet. The early nights do make it difficult to phone home to Africa in the evenings but her friends have become familiar with her routine. She feels that she is unable to explain to people that she and her husband have the ritual of going to bed early due to his brain injury so she tells them she does so to be submissive to his ways, which she sees as more socially acceptable.

Rita rarely leaves the house to have time to herself and she is in needs of respite and is hopeful that this will come if they make progress with access to services. Her life now centres around her husband’s routines and caring for him. He feels compelled to take up to six baths per day that she helps him with physically. This then generates a large amount of laundry. The warden in their sheltered accommodation automatically allocates her double the regular amount of time for use of the laundry to cope with this. The other women in the sheltered accommodation call her a, ‘good girl’ for coping with all of these tasks, especially as her husband is now well-dressed and he receives compliments in town for his appearance, which is contrast to his appearance before he married Rita. One person asked her if she married Peter out of pity, which at first she didn’t understand. She replied that she married him out of love and she married
him for a husband and not out of pity. She felt good when she made this
declaration. Each day Rita spends time sorting Peter’s paperwork. He is unable
to concentrate on detail in letters so she leaves him to open them and then she
deals with the business aspects. She cooks all of his meals except his routine
with the eggs. She encourages his independence by letting him heat soup, but
is conscious that he doesn’t do this properly. She cleans his car and tends to the
copious amount of plants he brings and places at the front of the house, which
look out place but she cannot persuade him to stop bringing them.

Little progress had been made in referring Peter to medical head injury services
until recently. He presented himself to the local accident and emergency unit
several times in two weeks, with bladder problems. Rita had the opportunity to
explain Peter’s symptoms to an out-of-area doctor who recognised Peter’s
bladder issue as not being a physical one but due to obsessive compulsive
disorder. This was the first time she has had any acknowledgement of this from
medical services and it triggered a referral to specialist services, which they are
still waiting for. She has faith that it will lead to progress and hopefully some
respite for herself. She cannot understand how the local medical services and
social services failed to recognise her husband’s symptoms when the charities
she contacted identified the problem immediately. Without charity support she
does not know how she could have carried on. Rita sees the local rural
community as uneducated and inward-looking, failing to acknowledge when
someone within their community is suffering. She sees their continuing failure to
acknowledge her concerns compounded by her skin colour. This failure to listen
and care is in stark contrast to her experience of city life in the UK, where she
was accepted and observed neighbours helping neighbours in times of difficulty.
She is trying to encourage the local community to address this issue and would
like to form an action group for a better community. She has met with a
Government Minister with this plight in mind.

The invisible nature of Peter’s head injury has been pivotal in how his life has
been. The people in local community and his family have not seen a man who
was disabled and therefore have not seen someone worthy of assistance.
Indeed, she didn’t see his disability when she met him; she saw a handsome
man who had courted her on the telephone and had thought he was romantic,
putting aside the unexplained requests for her to care for him. In spite of this she
makes it clear that she is not running away from the situation. She makes it
clear that she loves God and that she is also staying with her husband for God, as a kind of Good Samaritan of the Bible. She is also conscious of being part of a caring profession and it would reflect badly on her if she were to desert the man she married, just because he needs care. She loves her husband, but she requires help and she is hopeful for the future that this will be forthcoming and that she is at the beginning of trying to solve this situation.

Out of the adversity come a number of positive aspects to Rita’s story. Rita has a husband that she loves. She believes she has been placed in this situation for a reason and is doing God’s work. Actually being confined to the house for worship has forced her to engage with online interactive church services and extended her contacts far and wide, allowing her to meet people from other parts of the UK as well as overseas. She only hopes that she can soon receive some respite and her husband can begin to access rehabilitation he should have received over forty years ago.
Appendix S

The Remaining Analysis of Narratives (not contained in the main thesis or example offered above)

Participants 1;2;4;5;6;7;9;10;11
Appendix S: Analysis of narrative

Participant 1 – Rachel – A care giver’s story

Positional aspects of Rachel’s narrative interview

Rachel was someone who volunteered immediately when I attended a meeting of a brain injury charity to recruit and appeared just as welcoming and friendly on meeting her again, with an attitude that was one of being happy to help in order to make a difference. The environment was a little chaotic, with dogs and family around on arrival, but eventually settled down to a private interview.

She struck me as someone who had experienced much adversity in her life even before her husband had a brain injury and seemed a strong woman as a result of coping with this experience. She appeared much more confident during the interview than in front of her husband and I wondered if this confidence was due to familiarity with counseling sessions and one to one work, which she had had since a teenager. She had told her life story in public on a number of occasions through charity work.

By the end of Interview three I had the impression that Rachel had enjoyed the research participation, making a contribution to research and engaging with the technique of photo-elicitation and she asked me if she could keep copies of the photographs.

Analysis of Rachel’s narrative

Rachel is in her early 50s and has been married to Sam for over twenty-five years. She has a teenage son, Tobias and they live in a rural town in a predominantly agricultural area. Sam had a brain injury as a result of having a brain tumour removed, approximately nine years ago. Sam has fatigue and some cognitive issues. His current diagnosis is that his tumour has returned and he has a prognosis of three to five years. Rachel has her own health issues in that she has an hereditary progressive neurological condition, which her mother and grandmother died of in late mid-life. The family had always assumed that Sam would become a carer for Rachel but the reverse is now apparent.
She is white, British and grew up in a traditional family unit, ‘Mum, very much an old fashioned mum – stay at home’, (2/23-25). She anchors her upbringing as traditional by way of the discourse, with her father as the breadwinner and her mother as, ‘Cooking, baking, cleaning, hoovering, dusting, ironing. Joined the WI’, (2/27). There was always an air of mystery around visits to her maternal grandmother and presents an impression of emotional aversion as to how she found her grandmother, ‘Bedridden. She was a bit crazy’, (2/49-53). This underpins the story of how her own mother inherited the same condition and Rachel found herself being the main carer from a teenager, only to receive the same diagnosis herself some years later.

As a teenager she wanted to become a nurse but was prevented from leaving home to train, so as she could care for her mother who was deteriorating with physical ill health, mental ill health and behavioural issues. Home was an emotionally charged environment. She was in her mid-twenties when her mother died and then took factory work, met Sam and they married. She gave up work when Tobias was born. Today she is estranged from most of her wider family members.

Rachel's overall narrative tone appears to be pessimistic (McAdams, 1993). This may well be due to her negative experiences in her formative years (McAdams, 1993). She suggests that she may have been an unwanted child, as she was born much later than her siblings, ‘So I was kind of like a mistake or an accident of some sort’, (2/15). Rachel's life narrative shows some progression until the point of her mother becoming ill, when Rachel was about twelve years old. This was when a period of intense regression began (Gergen & Gergen, 1986). From the time of her mother being diagnosed with a serious degenerative neurological condition she was forced by her father to take over her mother’s day to day care. She lived with missing school to care for her mother whilst her father went out to work in a traditional male role, rather than him being his wife’s carer. She felt scapegoated for her mother’s illness by her father (Wills, 1981). She wanted to be a normal teenager and socialise with her friends but felt that she wasn’t allowed to be because of the family situation. She experienced both physical and verbal abuse. This carer role strain and abuse is not unusual (Campbell Reay & Browne, 2001). As a result of being a young carer she missed out on educational and social opportunities (Dearden & Becker, 2004).
Her father ensured that her mother’s disability was kept secretive due to the stigma of disability (Goffman, 1963). Altogether, this resulted in her foregoing a career in nursing which she had hoped to pursue. She describes the abuse she had from her father and mother by creating an image of an emotionally-charged environment, ‘bloody great bruise on me head’, (2/155). She also felt emotionally rejected by her father when he said to her, ‘Ooh, “Well I don’t love you any more. You’re no daughter of mine”’ (2/288).

During this time of turmoil her source of support was a charity worker, a genetic nurse, she describes as her ‘guardian angel’. She was encouraged by him to become involved in charity work to raise awareness of the medical condition, by speaking of her experience to both health professionals and the public. She became familiar with speaking to medical staff from this young age and in later years drew on this familiarity to confront medical staff when they failed to communicate effectively with her and her husband, having learned through experience (Dewey, 1938).

The early positive experience with charity involvement has been taken forward with her to present day and she continues to contribute to and look to charities to help people who require emotional support in times of illness, positively acknowledging a charity model of illness and disability (Shakespeare, 1994).

She gives the reason as to why she and Sam connected emotionally as, ‘And when I met Sam, he’d been through similar stuff’ (2/1076). They enjoyed socializing together through the factory where they worked, with darts and quiz nights as well as holidaying abroad and a shared love of music.

However, the dominance and lack of emotional recognition from her father has been repeated in her relationship with her husband, which may explain the continued engagement with charities, seeking additional emotional connection. Rachel positions herself as compassionate, ‘So I am quite tolerant and passionate in a way. Compassionate in a way to be understanding as best I could’ (1/18), which fits with the narrative about the occupational identity and persistence of care giving and wanting to be a nurse (Christiansen, 1999).

Rachel’s narrative has a significant element of disappointment in males not acknowledging positive emotions, by way of Sam and her father and draws on
gender stereotypes to explain this, ‘the typical male thing right’ (1/94) (Kite, Deaux & Haines, 2008). It is an example of the use of ‘splitting’ in the narrative to try and understand that some people react in such a way due to being male (Cashdon, 1999). She tries to prevent this from happening with her son Tobias: she facilitates him to express his emotions by way of encouraging him to engage with counseling. This is in order to maintain his psychological wellbeing, having two parents with severe health conditions.

Rachel draws on a significant amount of imagery in her discourse. She uses the imagery of a nightmare to describe the period from diagnosis of Sam’s tumour, which led to the brain injury, ‘your nightmare hasn’t begun yet. It’s when… it’s the aftermath when that will start’ (1/46-48). This suggests the formation of a mythic form of tragedy in Rachel’s narrative (Cashdon, 1999). This continues when she discusses the mood changes Sam underwent, ‘Half of you sees your husband there, Sam. And half of you sees this very Arnold Schwarzenegger and this very very quadruple bad mood’ (1/112). She relates her husband’s behaviour at this point to being similar to her father, with her being in a similar victim role. His behaviour could possibly be explained as a catastrophic reaction to neuro-trauma and resorting to self-centredness to cope (Hyden, 2008). Yet again she found herself in an emotionally-charged family environment, with conflict and role strain (Manskow et al, 2015).

However, today she is pleased that she persevered in the relationship, (described as a battle), due to resilience she learnt from past experience, ‘But thank God I stuck the three year out. I don’t know where I got the fight from! I think it came from built in armour that I’d acquired’ (1/336). She manages an impression as having survived adversity and come through this. As Sam is much calmer and friendlier today she feels that her patience has been rewarded, ‘And I feel as if a bit of justice has been done’ (1/414) and ‘Sam, Sam, Sam now is the person that he should be and how he’s thinking and how he’s feeling’ (1/530).

Today she sees her relationship with Sam much improved, ‘You’re more relaxed, you’re more secure, you’re safe, you’re happy and you trust each other. There’s that bond there’ (2/1108-14). She just wished that this could have happened earlier in their relationship. She has heard stories of people overcoming the adversity of an illness and it being positively life changing and
an awakening. She regrets this not happening with her husband (Conneeley, 2002). This narrative reads almost as if the romantic dream was not realised (Frye, 1957).

Rachel and Sam’s relationship had been underpinned by an understanding that Sam would need to eventually be Rachel’s carer, due to her degenerative neurological condition. However the roles have been reversed due to Sam’s brain injury and relatively poor prognosis, ‘The only thing I find a bit hard is like Sam’s always, up to this … understood that it’s me that’s gonna get poorly’ (3/1671).

Rachel appears proud of Tobias in her mother’s role, especially around his coping as a teenager, ‘I don’t know where he’s got his guts from, his spirit from’ (1/100). She was protective of him before his conception, in that she chose a donor egg so as she didn’t pass on her genetic neurological condition and now she worries about his future, having two parents with health issues. She does feel guilt in relation to her son, ‘You go on a bit of a guilt trip thinking what you know should we have had him’, (3/63) (Pakenham, Bursnall, Chui, Cannon & Okochi, 2006).

Rachel attempts stability in her current narrative with her engagement with spirituality and a mindfulness of living day by day (Kabat-Zinn, 1982). She sees her future in the hands of fate and tries to understand this as a phenomenon of the world she lives in, ‘This has to maybe happen for you to get where you’re going in life’ (2/847). This is a way of coping by turning psychic energy away from doubt and fear (Csikszentmihalyi, 1990). She has tried other coping mechanisms, such talking, negotiating or denial, ‘I’m a bit of a tough nut. I totally switched off’ (1/124), whilst expressing how resilient she is.

Rachel expresses a connection with her deceased mother and grandmother in terms of spirituality and links this to psychic ability, ‘Er but my Grandma was very psychic’ (1/756). She looks to how they would have coped with situations and believes that good will come eventually, ‘It’s how me Mum made me think’ (2/893) and ‘I’m a bit believer in fate and God and you talk to everybody that’s up there don’t you when them days are on’ (1/60). This is a form of reification (Strom, 2014).
Rachel demonstrates agency in the way she challenges medical staff when they lack respect in their encounters ‘I recognise things and I sort of had a quiet word with him after and said, “Where’s your bedside manner gone?”’ (1/36). This is due to the experience she has had with many medical encounters with her own family in the past. She was also encouraged by her ‘guardian angel’ (a nurse employed by a charity) in the past to be an advocate and give talks on her experience, ‘I forgot where it was now. Somewhere Hall but there’d be medical doctors and scientific people there’ (2/322). This suggests an early engagement with challenging a medical dominance in care. Rachel utilises objectification in her discourse by way of categorising medical staff, ‘Erm, I’ve met some awful people along the way, doc.. mainly consultants that were to do with medical’ (2/945). This is due to their medical model approach, which she challenges (Allan & Hall, 1988).

Rachel's main activities over the years appear connected to care giving. She was her mother’s carer from aged twelve to twenty-six and had wanted to become a nurse to be employed in caregiving, but her father prevented her. She worked for a while in a factory and then gave up work to be a mother. Ultimately she has become care-giver to Sam. She has continued with the advocacy and charity involvement over the years, by way of challenging and fund raising ‘We did lots of promoting the leaflets, booklets, handing stickers out. We did car boot’ (1/338). She would like to have a more social connection with others with illnesses, experiencing similar difficulties, possibly having gained support from charities since being a teenager. She has also been agentic by way of reading up on medical conditions herself and is especially interested in psychology. This could stem from the early aspirations to be a nurse and a form of occupational persistence or habituation (Kielhofner, 2008).

Rachel mentions other charity work she has done, such as fund-raising, advocacy and using her dog as a PAT dog. She engaged in the PAT dog therapy with altruistic intention (Babula, 2013), ‘I decided well instead of just sitting about, I'd hope me and him make somebody else’s day better’ (2/1815). This was connected to no longer being involved in the charity she had been since a teenager and missed the social capital of this engagement (Bourdieu, 1986). She enjoys talking to people to try and help them by drawing on her own care giving experience.
Alongside caring for Sam and Tobias, Rachel gains emotional support from a female friend, as a form of social capital (Bourdieu, 1986), ‘But we seem to just sort of have a lot in common. She’s gone through a lot’ (3/841). She discusses helping each other through difficult times, including Rachel helping her when she felt suicidal. Besides Rachel gaining support from her friend it is another example of Rachel drawing on her care giving.

Other activities involve holidays, which are restricted now due to finances and Sam’s health, but she longs for these and would like to move to Italy. She would like to do anything that allowed her to get out of the house from the present situation, even though she claims a strong relationship with Sam now ‘But I would rather sit there than be stuck here’ (3/591) and ‘I don’t know what it is. I’ve got itchy feet. Restless feet’ (3/329). This is almost like a form of escape from the uncertain situation about both his and her health situation. She feels guilt for not being at home with Sam, but feels an urge to get out (Spillers, Wellisch, Kim, Matthews & Baker, 2008). Besides not being happy with the home environment she is not happy with the rural town where they live and see it as having few facilities and activities and public transport is expensive. She sees herself as being cut off from family and friends, ‘You see so. I’ve been very cut off’ (3/2288). This may relate to her being, as she describes, needy. A significant amount of time is spent attending hospital appointments and she is the main driver, which Sam is critical of as before his brain injury this was his role.

The activities she engages in with Sam include playing music, games and watching television. She expresses a love of reading. She is passionate about some musicians and finds solace in the words of their music ‘the tour was called ‘Forever more’ and every word on that, everything relates to me’ (3/2379-83). This is an extension of the need for connection with others when she describes herself as ‘needy’.

She also enjoys engaging in spiritual activities and is pleased now that Sam will attend with her ‘You can go in and chat with any of the Buddhists any time you want. But the trouble is, is I’ve always been into this spiritual side. God side, brain side. Sam hasn’t’ (3/2532-36) (Baldacchino & Draper, 2001). 
She becomes upset when people don’t appreciate the hidden nature of hers and Sam’s disability, just because it isn’t visible (Gordon et al, 1998). What she doesn’t understand, in terms of relationships and personal values, is why people don’t return the kindness she feels she has offered them, ‘Why? What have I done? Cos, all I’ve done is been kind, nice, helpful’ (2/690-694). This relates to her family past and present and her husband. She has tried to follow a code of being an active self-conscious being (Bargh, & Chartrand, 1999).

Overall, Rachel’s narrative shows an occupational persistence that is rooted in caring and medical knowledge. She wanted to become a nurse but was prevented, so as she would care for her mother. She built up resilience in order to cope in a highly emotionally-charged home environment and has found herself in a similar situation in recent years. Many of the activities she mentions in her narrative suggest caring and she positions herself as compassionate with an urge to help others.

She became an advocate for people with neurological conditions and built up a positive image of the charity model of disability with confidence to challenge a medical model (Allan & Hall, 1988). She misses this type of activity today. She is unsettled at home and her activities centre around going with Sam to visit coffee shops or going out on her own and visiting her friend. She is unsettled in the home and by her home situation.

In the past she has had some low points where she has attempted suicide and engaged in obsessive / compulsive behaviour. She still has some obsessional tendencies, like avoiding the colour red wherever possible, but it no longer prevents her from engaging in normal daily life. However, she is left with background anxiety about Sam’s past volatile behaviour reoccurring at any time, ‘Boom. Suddenly, all it stopped. Now that were weird cos I’ve stayed on the red alert’ (1/171).
Appendix S: Analysis of narrative

Participant 2 – Sam – A man with a brain injury who is terminally ill

Positional aspects of Sam’s narrative interview

I’d previously interviewed Sam’s wife, Rachel and it was interesting to see the difference in the two narratives: Rachel dwelt considerably on the difficult period after Sam’s diagnosis whilst Sam only made brief acknowledgement to it. This could be due to not wanting to present himself in a negative light, to me the female researcher.

I was conscious that I connected less with Sam than Rachel, due to the gender difference. His approach was different in that he utilised humour in the discourse, to lighten the conversation, but then he did become more serious during the progress of the interviews. I was also not prepared for the fact that he was terminally ill, as I had not taken this into account before the interview, but hopefully I showed no outward sign of this.

Analysis of Sam’s narrative

Sam is in his early fifties and lives in a UK rural town in a predominantly agricultural area. He is married to Rachel and they have a teenage son, Tobias. They have been married for over twenty-five years. Sam had a brain injury as a result of having a brain tumour removed, approximately nine years ago. He has fatigue and some cognitive issues, including executive functioning issues, which affects him by making multi-tasking difficult (BSRM&RCP 2003; Headway, 2016b). His current diagnosis is that his tumour has returned and he has a prognosis of three to five years. Rachel has her own health issues in that she has an hereditary progressive neurological condition, which her mother and grandmother died of in late mid-life. The family had always assumed that Sam would become a carer for Rachel but the reverse is now apparent, forcing an unexpected biographical disruption on Rachel also (Charmaz, 1999).

He is white, British and grew up in a mining village with his father and older brother. His mother was absent during most of his developmental years, (from
the age of four). He holds his father’s memory in high esteem, ‘he was a character and he was, you know, no matter how hard times were, he was always there’ (2/50). His father died when he was fifteen and he spent some time finding his way in life and eventually married Rachel. He recently gave up work in a local shop, due to fatigue issues and being cognisant that his time left is limited. Despite him having a terminal diagnosis he is determined to make the most of his time left, such as making a cross stitch for his son to remember him by, knowing that his own father did not have any possessions to leave for him when he died, which he would have dearly liked. It is as if Sam’s only legacy of his father is in his memory and he would like to leave an object as a legacy for his own son (Frankl, 2004).

Sam’s narrative tone in primarily optimistic. This may be due to the positive tone of his childhood experience (McAdams, 1993), which he sites as influential on how he sees the world today. He was brought up in materially-impoverished circumstances, by a father who fought hard to parent him alone. His mother left when he was four years old and took many of the household possessions but this, if anything, strengthened his relationship with his father who loved and protected him. He declares that he worshipped his father. Even though he felt loved and cared for his life wasn’t comfortable, ‘I was brought up hard and er, life wasn’t easy but we got by’ (2/170), reflecting a hardy personality (Sanders & Suls, 1982). His narrative does not suggest that he was emotionally impoverished, which may underpin his positive narrative tone (McAdams, 1993). Sam describes his life as fairly happy until his mother left when he was four. He creates an impression of divine intervention when his mother was foiled in trying to take him to live with her, ‘I hadn’t realised it, but that one night, my mother had been waiting at the top of the school lane’ (2/68-70) (Strom, 2014). He also uses imagery to suggest that his dead father may be watching over him, ‘And I hope if he’s looking down, I’ve repaid that in some way’, (2/178) (McAdams, 1993). This is almost as if he were hoping to repay what he has been given before he dies himself, giving satisfactory closure to his narrative before he dies, (Cashdan, 1999).

His father struggled to move the family out of this regressive period and drew on his resolve to dedicate his life to his sons and survive this adversity, which Sam respects him for. His father’s legacy remains prestigious in his narrative, ‘And er, absolutely broke my heart when he died’ (2/144). It is as if Sam romanticises his
upbringing (Frye, 1957). Sam forms an identity of having been brought up with good honest values, despite being materially impoverished, ‘Life wasn’t easy but we got by and er, if it meant doing without a lot of the time, it did, but god he did (father), he did everything he possibly could to bring me up right’ (2/174-180). He gives an image of his father being the most important person in his life, ‘I suppose I worshipped me dad’ (1/14). He talks about his father coming back from WW2 to no job and how he made a home for them, despite little money. He taught him a strong work ethic and the value of money, which he carries with him to this day (de Botton, 2009).

Sam makes sure that the listener has a positive impression of his hard-working father, who brought up two sons on his own, yet objectifies him as ‘a character’, (2/50), which almost introduces comedy into the person and suggests that although he portrays him as overall positive there may be some negatives too, acknowledging that he wasn’t always a well-behaved person or role model (Tajfel & Turner, 1979). It suggests he was an underdog who came through times of adversity, almost romanticising his memory of his father.

Sam spent much time on his own doing solitary activities as a child, due to his family circumstances. He was never bored and always found things to do, even though he was materially impoverished. He enjoyed playing football with the local boys and suggests a community spirit, ‘So everybody played together’ (3/306). He played cards with his father and brother. He didn’t enjoy his school experience but enjoyed some of the subjects.

Sam did not gain entrance to the grammar school. He sees this as a social injustice (Cohen, 2006), ‘They took the highest marks, a lad and a lass and they got sent to the local grammar school. The rest of us had to go to what became a comprehensive’ (2/468-72). This virtually ruled out his chances of attending university and meant he was destined to follow his father to be a miner, which he didn’t want. Even today he objectifies miners as being victims of their social circumstances when he discusses his father’s death, ‘And so he got a job down the pit which invariably killed him,’ (2/138) (Berger & Luckmann, 1966). A regressive period followed; his father developed cancer when Sam was twelve and he missed schooling in his mid-teens, in order to prioritise spending time visiting his father in hospital before he died. This is an epiphany moment in Sam’s life (Bruner, 1990). He has always wanted to fulfill his academic potential
as a result, 'one of my lifetime ambitions was to go to university' (1/264), and carry on the legacy of his father’s values.

He missed out an opportunity to join the navy due to health problems. He sought to be reunited with his mother, which did not work out. Sam describes the unsuccessful period of living with his mother in his teens as being emotional and his feelings as, ‘I was in a bit of a mess anyway because of me dad just having died, I wasn’t thinking straight’ (2/586-90). He had an unsuccessful marriage at a young age. Then he met Rachel, whilst working in a factory. A period of progression followed for a number of years, where they settled into marriage and eventually had a son, Tobias. Work was on a factory shop floor and then in a local shop, where he not only sold hardware items, but also gave advice. He voiced his opinion at work that he disagreed with sales bonus schemes and favoured the offering of sound advice to customers and hopes that even today, the customers respect him for that (Gergen & Gergen, 1986). When they had been married for about eighteen years he received the diagnosis of a brain tumour. The tumour was removed, resulting in a brain injury (BSRM&RCP, 2003), and a period of turbulence followed (Yeates & Bowen, 2014).

Sam is quite clear that he does not consider that he reached his potential in life (Csikszentmihalyi, 1990). He makes a number of statements about being intelligent but not gaining qualifications due to personal circumstances and subsequent biographical disruption (Charmaz, 1999). He manages an impression of being intelligent even though he didn’t achieve qualifications, ‘I like to think of meself as quite intelligent, you know and articulate’, (2/434). He is careful to make it clear that he passed all of his tests to join the navy, but was awaiting a nose operation and this was the reason he couldn’t join, ‘I was accepted, passed all the tests and everything, but I failed my medical at the time’ (1/20). He attributes going in to factory work to having to be earning a wage to make a contribution, ‘simple as that. Money was tight’ (1/24).

His long held desire to go to university was realised when he began a part-time history degree. This persistence in attempting to realise this desire is declared when he states, ‘So I wanted to stretch meself basically and always have done’ (2/902). He first took a number of educational courses, such as learning languages, as a precursor to being able to enroll on the university programme. He gained enormous pleasure in study, ‘I love history, I love me course’,
However, now the studying has become increasingly difficult to maintain, due to his brain injury symptoms, such as fatigue and executive functioning (BSRM&RCP, 2003; Headway, 2016b), and he is limited in his academic writing skills, ‘it’s gotta be 2000 words and get it right and that’s, that’s difficult’ (3/1709). He realises that he could still study without it being for the degree but he now sees sitting in a library all day as selfish, in that Rachel won’t really want to do this with him. His narrative exhibits an occupational persistence or habituation of a love of history (Kielhofner, 2008), with an underlying life goal of teaching it, ‘I’d love to have taught history. That was the erm, sort of goal I suppose’ (2/1029-31).

His short life expectancy means that may not live to the completion date of the part-time degree also. He is considering carefully how to spend his remaining time to best advantage. He hopes that it has been recognised that he has always worked hard by the people in the small town where he lives. But with little time left he wants to spend more time with his son and wife and for this reason he has given up his paid employment and studies. ‘I’m busy at home spending some time with me family (3/30) and wanting his remaining time to be fun, ‘I don’t want it all to be work. I want it to be fun’ (3/1555). This includes the importance of his remaining time in the father role, ‘I thought I want to spend what time I’ve got left being a dad to Tobias’, (2/382-4) (Hogg & Vaughan, 2014). He tries to instill in Tobias the values that his own father taught him, such as enjoying himself but not bringing trouble home and appreciating the natural environment and people over material possessions. Today, he becomes cross when Tobias says that he’s bored when he has so many choices for activities, ‘The one thing I will not tolerate is Tobias saying he’s bored. Don’t accept that’, (3/2375), due to the fact that he was never bored as a child and had few possessions.

He does have moments when he feels dejected due to his life expectancy (Headway, 2016b) and he feels considerable physical pain but he puts this behind him and involves himself in solitary creative hobbies or activities with his wife and son. He wants to be able to leave Tobias something to remember him by and to ensure Rachel has enough money to pay for his funeral, again trying to put proper closure on issues before he dies (Cashdan, 1999).
Sam still has a strong working class work ethic (de Botton 2009). He values the person over material wealth. He attributes this to his father, 'He taught me the value of things as well you know. If I wanted some money to do anything I had to go and chop sticks for the fire' (2/202-4). He would now identify himself as someone who has made his working contribution to society, 'I've done my stint', (2/1169) and describes himself as not being able to work due to health reasons, 'I would now say, well I've just retired through ill health' (3/16). This discourse serves to separate him from those who are objectified as too lazy to work (Willig, 1999).

He is a principled man who continues to support his childhood football team, the underdogs, over bigger, more glamorous rivals. He attributes his time spent alone as a child to be the reason he enjoys solitary activities as an adult. He has a love of model making and follows a WW2 theme with this, connected to his father's stories of being in the war himself, 'Erm, so I was lived on what stories of what me dad would say, you know' (3/616). He also enjoys embroidery and cross-stitch. He tries to understand the perspective of the underdog in a number of avenues of his life, possibly due to seeing himself as having come from this position. The habituation of the championing the underdog continues (Kielhofner, 2008), when he discusses the Apaches and how he loves to portray them in cross stitch pictures now: his childhood love of cowboy and Indian stories, respecting the Indians and now still championing the underdog, over the cowboys, 'Er, they were cheated, they were lied to, they were robbed basically'(3/1135) is how he thought about them from childhood.

Sam defends his male identity when he discusses doing a predominantly female activity in cross stitch (Tajfel & Turner), 'I don't see what's wrong with it. If I can sit there peacefully and and do something like that cross stitch. I'm not bothering anybody' (3/248). Importantly he finds the activity relaxing and he is working on producing something that he can leave behind for Tobias, 'I hope Tobias at some point thinks, oh me dad did them' (3/1163), which is akin to leaving a legacy behind to be remembered by. Sam regrets that his own father had nothing to leave him, 'Lived through the depression, went to war, came back. He had nothing. He didn’t have anything to leave me', (3/1185-7). This is a form of righting some wrongs in his own life before he dies (Frankl, 2004).
Sam has a passion for reading, especially local history and biography, again linked to solitary time as a child, ‘I’d be on me own at home. And that’s how it developed, me love for reading as well’ (3/360).

He has a love of pets, especially dogs. His dogs have both been from the rescue centre and one was described as, ‘nobody’s wanted him’ (3/1751). This is another example of Sam’s habituation of trying to find justice for the underdog (Kielhofner, 2008), possibly similar to the recognition he would like for his father, having been in WW2 and then having a difficult life as a single parent who had a premature death. He enjoys the routine and habit of walking the dogs each day. He enjoyed this even more when they lived in a more remote location in that he could walk the dogs for miles and not meet anyone else. This links to his pleasure in the natural environment, enjoying plants and wild life, such as birds (Morris, 1888).

Sam identifies himself as a good driver, ‘give me a full lobotomy, I’d still be better than most of the people out there’ (3/853). Sam’s brain injury symptoms have required him to give up his driving licence, which has been significant for him, ‘That was another thing I didn’t mention. It’s come to me now. Erm, it was quite an important part of my life’ (2/1295-7). His reduced performance capacity impacts on self-concept and identity (Hoogerdijk, Runge & Haugboelle, 2011). One of Sam’s fears for the future is loosing functional occupational performance and he has asked his consultant about the chances of this happening, ‘I said to him, what’s the odds of me loosing a function?’ (1/140). This could be due to Sam having a personal identity of being independent and of hardy personality, despite being terminally ill (Sanders & Suls, 1982). Indeed he mourns the loss of being able to drive in stating that he feels disempowered by this.

Sam has spent a considerable amount of time as a patient in the past nine years. Initially this was a negative experience, which he was left feeling angry about, when the GP gave him a very limited sick note for what Sam thought were serious symptoms, (the first signs of his brain tumour). He was upset that the GP thought him a malingerer, when he actually holds values of being hard working (de Botton, 2009). His experience with his current GP is quite the opposite of this, now he has had his brain injury, ‘and he’s been true to his word and he’s looked after me fantastically ever since’ (1/763). His current treatment does leave him with a number of symptoms, such as hair loss, skin problems,
physical pain and emotional lability, besides the cognitive symptoms of the brain injury.

Previously Sam has enjoyed travelling abroad with Rachel but his brain injury symptoms make him fearful of flying, 'I don’t want me head to burst, cos that’s what it feel like.' (2/1451-3). His travel hopes for the future are to Scotland and to visit places that were meaningful to his father, 'I’d love to do the erm, battlefield tour, to see where me dad went running up the beach in Normandy.' (2/1471), indicating his identity through kinship (Lawler, 2014).

Sam conceptualises his life with the imagery of a clock, ‘clock’s ticking. I’m very conscious of that now’ (2/996). He also identifies with the imagery of a cancer charity advertisement to explain the way he feels too, ‘just drops to his knees and that’s exactly what it feels like. As though somebody’s just pulled the legs out from underneath you’ (1/152-4) (McAdams, 1993). He is agentic in his coping strategies around being terminally ill, ‘You’ve gotta sort of like rise above it and carry on. Keep calm and carry on as they say’ (3/1729-33) (McAdams, 1993). He has made changes to his lifestyle to try and, ‘buy me ten years’ (3/1321), by stopping smoking and reducing his alcohol intake, indicating his desire for a health locus of control (Sanders & Suls, 1982). This is akin to rejecting the human malaise from a stalled plot (Frank, 1995). Sam’s narrative includes much of his future script and how he would like to spend his time in the coming years. This could be due to the fact that he has been told that his life expectancy is short and he wishes to ensure that his time is spent meaningfully.

He admits that he has not always behaved well towards his family since his diagnosis some nine years ago but sees himself as having come through this difficult period. He values the support him and his family receive from counseling and the relationships and treatment from the long-serving medical personnel he has been involved with, appreciating the social capital available to him (Bourdieu, 1986).

His work ethic is anchored in always trying hard, ‘You should be able to think, well I want to be the best. I want to do me best’ (3/2095) and does not see money as being a motivating factor (de Botton, 2009). This could be why it affected him deeply when he thought that the doctor was dismissing him as a malingerer when he had the early symptoms of his brain tumour, ‘but to dismiss
me like that and not even do any form of tests’ (2/724). This was an insult to his personal identity (Lawler, 2014). He also uses objectification in the discourse when he discusses people who are malingerers, in that he was dismissed as one by the GP. His GP had formed an impression of him as a potential malingerer due to the social identity of him being working class and the GP making assumptions around that (Berger & Luckmann, 1966).

Although Sam makes it clear through the discourse that he has a strong work ethic and values doing his best over material reward he is currently experiencing an occupational alienation in terms of work. This was due to fatigue making him, ‘absolutely and utterly exhausted’ (2/1139), when he finished his work for the day. This is due to wanting to spend his remaining time living, engaged in meaningful occupation, ‘and then two weeks ago, I’m ….. went to see my doctor and I made a decision that I didn’t want to carry on working anymore’ (1/296). The validation of this decision by his GP, who from a medical model perspective is in authority, justifies his giving up work when he carries this strong work ethic (Berger & Luckmann, 1966; Willig, 1999). Finishing work has given a degree of occupational balance as a result, ‘I’ve probably been more relaxed over the last two weeks, than I have been for years’ (1/312) (Christiensen & Matuska, 2006). He had an internal conflict due to an uncertainty about his future and not wanting to waste time he had left. He predicts that he will miss the social contact of work, ‘I’ll miss some of the people but I wont particularly miss the job as such’, (3/2109). He does become frustrated navigating the benefits system and having to explain to people that he is terminally ill. Ultimately the father role, in his remaining time, is crucial to him, ‘And that’s another reason why I packed in the other week with me job. I thought is want to spend what time I’ve got left being a dad to Tobias’ (2/380-4) (Hogg & Vaughan, 2014).

Overall, Sam’s narrative cannot be described as a restitution narrative, as Frank states these narratives do not belong to people who have a terminal diagnosis (Frank, 1995). However, Sam does seem to have an acceptance of his shortened future script and has taken steps to manage his remaining time with his family, with a justification for going against his values of being hard working. This is almost akin to a narrative underpinned by Erikson’s final stage of psychosocial development, of integrity versus despair (Erikson, 1959), around end of life, even though he is some years short of the usual life expectancy.
Appendix S: Analysis of narrative

Participant 4 – Bruce – A retired policeman

Positional aspects of Bruce’s narrative interview

After the first interview I felt quite disappointed and believed that Bruce was potentially not a suitable participant to take part in the research: it involved telling his life story and he had severe memory problems with no recall of his life pre-injury, (which was only about five years previous to the visit). He was unable to recount a narrative history. He had been suggested as a suitable participant through a brain injury charity I had contacted. I wondered if the charity worker had been prompted to suggest that I contact him to invite him to take part, as his situation was so tragic and it was a good example of the help that the charity can provide.

However, by the time Bruce had undertaken the final interview and engaged with the photo-elicitation exercise it was apparent that he was very suited to the research indeed: his lack of narrative was as significant as a detailed narrative from another participant. It revealed that his inner psyche held very little narrative for him to draw on in daily life. Producing the photographs was a huge catalyst to discussion of his current occupational engagement and the value and meaning that the activities held for him.

Analysis of Bruce’s interview

Bruce is in his forties. He lives in a large period house with extensive gardens, surrounded by picturesque countryside in a remote rural setting, close to a small hamlet. It is a very peaceful setting. He worked as a policeman up until he was assaulted on duty and had to retire as a result, about five years previously. The acquired brain injury from the assault was so severe that he now lives with symptoms of complete memory loss of his life prior to the event, deficits with short term memory, executive functioning, (such as sequencing), and also experiences fatigue and flat affect, (which reduces his ability to feel and express emotions), (BSRM&RCO, 2003; Headway, 2016b). From a physical perspective he has balance problems and is only able to walk short distances and requires a walking stick for assistance, even indoors. He has both auditory and visual
sensory hyper-sensitivity, which limits his noise and visual tolerance, (NHS, 2016). His preferred environment is quiet, peaceful with little auditory or visual stimulation.

Bruce is married and his wife is self-employed, which requires her to be away from home at times. He has a young son, Finn. His niece, is employed as an au pair and lives in the family home to help with childcare and assist Bruce.

Bruce’s narrative tone is neither optimistic nor pessimistic (McAdams, 1993). This is because he tends to relay mainly factual information, due to the nature of his brain injury symptoms. He also makes it clear that he finds it difficult to feel and express any emotion (Headway, 2016b). There are elements of feeling in his story to a small degree when he talks about a number of issues, but it is limited. For example he talks about growing a pumpkin for his six-year old son for Halloween, which obviously holds some meaning for him in his role as father, ‘I'm growing a pumpkin for, for xxx’s Halloween so I water and feed that a bit more than the others. All I, hope it gets a decent size’, (3/430-436). He talks about feeling lucky that his wife is prepared to stay with him. He also has a strong element of wanting to be involved in helping people: now that he is a retired policeman it is a legacy that he is left with and still wants to be part of. This is akin to habituation in that he did this in his previous role and holds on to this as part of his occupational identity (Christiansen, 1999; Kielhofner, 2008). He makes mention of the produce from his garden being used as a donation to a community group, who have little access to fresh produce and this holds importance for him. He also paints oil pictures and gives them to members of his wider family, who he acknowledges have helped him since his brain injury. He speaks highly of the charity that has given him support.

Much of the rest of his life story displays little emotion, either optimistically or pessimistically. He has lost all of his memory pre-acquired brain injury (Headway, 2016b), yet expresses no dismay at this, as would be the expected reaction. He simply states it as factual information. He has little elaboration in conversation thus making his conversation stilted and flat. He also tires easily and can only concentrate for short periods. The theme of helping others is accompanied by a theme of seeing progress as important in life, ‘Since the, I know, I, I, er like to, sounds a bit silly, but I’d like to to, to help people. They, that’s important. Er, well, I suppose it's, it's good for, for a person to, to have a
career and progress’ (3/547-555): he misses his paid employment as he is no longer able to progress with his career and he discusses progress in terms of his gardening, ‘I suppose it’s just another something that I can do, feel I can progress and do. It gives me an interest’, (3/172-176). When asked about any intrinsic reward gained by contributing to the community he states that he does not feel an emotion from this, but has knowledge, i.e. a cognitive understanding, that it is a good thing to do, ‘I, I don’t have huge emotions about anything, but I know it’s a good thing to do’, (3/305-311). Other than discussing progress he appears to have no future plot in his story and lives in the here and now (Polkinghorne, 1998). He does gain satisfaction from being part of the growing process i.e. the seed in the packet being transformed to the food on the family plates.

Whilst the tone displayed is neither optimistic nor pessimistic it could be argued that it is neither objective (McAdams, 1993): there appears to be a lack of tone due to his cognitive limitations and absence of narrative.

Bruce relies on the hearsay memories from his family to recall his narrative pre-injury, due to memory loss, ‘I have sort of prompts where my family might talk about events so sometimes things’ll be said that are sort of second memories. I think there’s a way to, to describe it’ (1/8). From this he believes initially his story was progressive, being involved in sports and other outdoor activities (Gergen & Gergen, 1986). His vague description of his identity pre-injury is suggestive of being physically active, although he doesn’t actually recall this himself, ‘I used to be very into outdoor type of living and sports and things’ (1/20). Now he does not have the physical ability to check if he retains any of the necessary skills to verify this. He worked as a policeman. A major regressive episode occurred when he sustained an ABI as the result of an assault whilst on police duty about five years ago, ‘I know I was a policeman and I was assaulted and then retired’ (1/18) (Gergen & Gergen, 1986). Bruce describes the event that caused his ABI as ‘the incident’ (1/4), suggesting that it is the key focus of his life narrative (Charmaz, 1999). He has two brothers and one sister. He knows his marriage began prior to his ABI and he became a father prior to the ABI, as he can work this out due to the current age of his son.

Since then he has made some progress but is left with significant symptoms of ABI, which leaves him able to manage his own personal self-care and otherwise
engage in only a few activities. A rehabilitation charity has encouraged him to engage with some activities, which have helped to promote his feelings of self-worth, through helping others, ‘Yes, I didn’t, I didn’t have much self worth and I wasn’t very good at dealing with it to begin with but over time I, with that and family has made it easier’ (1/154). This suggests a combination of the rehabilitation activities and the social capital of the family having an impact on his recovery and coping (Bourdieu, 1986; Kneafsey & Gawthrope, 2004). He talks about doing things to try and move forward in his life, suggesting a desire to continue with a progressive narrative (Gergen & Gergen, 1986).

With respect to his family and home, he describes some of the aspects of his life as normal, such as his son, ‘Just normal little boy’ (1/124) and his dog, ‘just the normal house pet’ (1/324), suggesting nothing remarkable about either of them. His view of his marriage, ‘Just lucky that I have a wife that is prepared to stick with me’ (1/362), indicates that he values her commitment in spite of his current life situation and limitations. He is also pleased with his rural physical environment, ‘I, I think we live in a very nice place.’ (3/363).

Bruce appears autonomous, if not agentic, albeit within the domains of his own environment (McAdams, 1993), due to the support he receives. He appears to accept that he can no longer engage with activities he once did, such as work, but he has no memory of other past activities to mourn. Being unable to engage with his past occupations will impact on his identity, even though he may well continue to hold strands of it (Nochi, 1998; Gelech & Dejardins, 2011). He has some agency in engagement with such as the gardening and painting, possibly due to his commitment to believe that progress is good for him and helping others with the gardening produce and saying, ‘thank-you’ to his family with the finished paintings he creates (McAdams, 1993).

Currently his range of activities that make up his daily repertoire is limited. A brain injury charity has been involved in his rehabilitation for some time. He prefixes an early discussion of the charity with the words, ‘And they er, they’re a very, very good group’ (1/144), anchoring their value to his rehabilitation (Berger & Luckmann, 1966). They thought that gardening might be a good activity for him to take up, especially as he lives in an environment that is ideally suited to it, with a garden with lots of space,
'And they thought that gardening, and we have a space, was a good idea.' (1/144). It is clear that his engagement in the activities instigated by the charity has significantly helped with this and he is grateful for this social capital as a result (Bourdieu, 1986).

The garden has been adapted to suit his physical needs, such as the inclusion of raised beds for him to manage at a suitable height. A poly-tunnel enables him to continue with the activity indoors. He is limited in his engagement due to his mobility and headaches. The gardening allows him to have physical exercise, help local community groups with the vegetables he grows, have social contact with other gardeners, engage with competitive growing, produce things for his wife and son and gives him the satisfaction of seeing seeds become food for the family to eat, 'I, I enjoy the process of sowing seeds and all the way through to that.' (3/58). He sees value in helping others (Frankl, 2004).

He takes particular care with growing a pumpkin for his son, which is important to him in his role as father. It is for the celebration of Halloween, which is enjoyed by children in his culture. He would like to be able to do more physical activities with his son but he is unable to and this limits his father role (Hogg & Vaughan, 2014).

He has begun painting in oils and acrylic, ‘I also love trying to paint’ (1/8). This is a new skill he has learnt, which is a demonstration of progress for him. He gains enjoyment from engaging in this activity and also gives the finished product to his family, who have helped and supported him since his injury, ‘No I think it’s just I’m allowed to try and do some things that are er, great one to see if I can do something and I think the, the most of the ones I do, I give away to family or things.’ (3/329-333) Contributing to the family and community demonstrates his habituation of helping others, like in his policeman role (Kielhofner, 2008) and that strands of his former self are still present in his identity (Nochi, 1998; Gelech & Dejardins, 2011).

He engages with physiotherapy for maintenance and prevention of further physical deterioration. He uses a walking stick to aid his mobility and a number of pieces of equipment to manage his personal activities of daily living. He uses the diary feature of his mobile phone to prompt his memory for daily tasks, including planning and organising his gardening activities.
He does sometimes cook the garden produce with the help of his niece and makes soup. This is a relatively simple activity as it does not require high demands on executive functioning in order to be successful (Headway, 2016b) and thus suits Bruce’s ability, ‘I make it up. I just chuck it all in’ (3/94-96). He takes an interest in current affairs and likes to watch the news on television, but otherwise he may only watch a film on television but he rarely remembers the content afterwards due to poor memory.

Bruce expresses disappointment at relying on his wife to drive, in that it makes him reliant on others, as there are few transport links in the rural location. It may also impact on his previous role as driver and personal identity (Tajfel, 1978; Hogg & Vaughan, 2014). Otherwise, the rural location is suitable, due to its peace and quiet, compatible with his sensory hyper-sensitivity (NHS, 2016). He also enjoys the physical beauty and he feels comfortable within the boundaries of his home, ‘Erm, I like, know I like my own space, I like to do, stay within the boundaries of what I feel, feel comfortable with’ (3/22-24). It may be that the home environment offers him security in a world that is now difficult for him to cope in, with potential to fail, or a need to withdraw quickly (Maslow, 1943). At one point even being a passenger in a car could bring on a blackout due to too much visual stimulation. He rarely goes to shops or restaurants due to this hyper-sensitivity (NHS, 2016). He creates an impression that his quiet life in a rural setting suits his needs, in terms of his hyper-sensitivity and that his lack of social engagement is not an issue. Contentment is suggested with isolation but this may simply due to his flat affect, or a resignation to his limits of coping with demands of daily living and finding an environment that suits him. This is reinforced when he states, ‘almost like an overload’ (1/98), indicating that he has a low limit to his neuro-stimulation.

In his role as husband he feels lucky to still have a wife, given his current circumstances. He considers his neighbours as friends, who offer support in terms of transport. This exemplifies the importance of social capital for people with ABI (Bourdieu, 1986). He no longer has the role of policeman but considers himself a retired policeman and still feels it is important to contribute to the community and help people, ‘Since the, I know I, I, I er like to, sounds a bit silly, but I’d like to, to help people. They, that’s important’ (3/547-549). He sees this as part of his progress in life. This can be considered strands of occupational
identity, brought forward from his pre-injury status (Nochi, 1998; Gelech & Dejardins, 2011). He discusses the importance of career and progress and his continued engagement with this, by continuing to help people in the community.

As Bruce’s narrative is more factual and brief, few images or impressions are created through his discourse, due to his flat affect (McAdams, 1993). In terms of relationships he expresses gratitude to those who support him, such as his family and the charity. He is appreciative of his wife in that she has remained in the marriage, ‘Just lucky I have a wife that is prepared to stick with me’ (1/362), perhaps as an example of his loss of self-worth he talks about in other parts of his narrative (Nochi, 1998). He values his neighbours in the support they offer and mentions their help with transport.

Bruce considers it important to have a relationship with the local community, in so far as he can contribute to it, even if he doesn’t socialise within it. He suggests that some aspects of his life cause concern over expense, such as transport, his wife buying flowers and finding a way to manage his care needs and childcare. A number of times in his narrative he uses the word ‘struggle’ (3/254; 3/523), to suggest that life is not easy for him (Berger & Luckmann, 1966; Willig, 1999). He draws on words that suggest progress, such as ‘gives aim for me’ (3/207), ‘I try and do things that I can do to try and move forward’ (3/557) and ‘the gardening is helping me forward’ (3/607), indicating that he tries to be agentic (McAdams, 1993).

When discussing some of his activities he uses words such as ‘creating’ (3/32) and ‘love trying to paint’ (1/8), suggesting a pleasure from engagement in activities (Csikszentmihalyi, 1990). He also makes suggestion as to the reciprocal helping role he is involved with, ‘people come and help me to, to produce vegetables for others that aren’t able to’ (1/8). This indicates that he is grateful for the help and that others may be grateful for his contribution too.

Overall, Bruce has a limited pattern of activities, due to his physical and cognitive deficits. It is evident that his occupational engagement with gardening is very important in his life and fulfills a range of functions, such as exercise, pleasure, competition, contribution to the family and community and together this increases his self-worth. He also takes pleasure in learning a new skill in the
oil painting and the personal development aspect of this, as well as being able to give gifts to his family by way of the finished product.

There is an occupational persistence or habituation of wanting to help the local community, rooted in his occupational identity as a policeman (Kielhofner, 2008). He now does this by way of allowing others to use his garden for their rehabilitation and provide produce for people in the community who don’t have ready access to it.
Appendix S: Analysis of narrative

Participant 5 – Susan – A nurse’s story

Positional aspects of Susan’s narrative interview

Susan was the only participant who requested to be interviewed at the University rather than her home. I came to understand that this was probably indicative of her narrative: she had given up work as a nurse for health reasons, yet held on strongly to her nurse identity. Coming to the University was part of establishing a routine in another healthcare setting, as she had just become a service user engaged with delivery of healthcare programmes. Re-establishing a routine was important to her also. My not having the external clues to her home left a gap in her daily living background to me.

Because Susan had a role at the University, of telling of her illness experience to healthcare students, I was worried that this influenced the focus of the interview and it may well have done. I observed that her discourse was strongly healthcare orientated and she was confident in her use of medical terminology.

When we began the interviews I was unaware that she had had a secondary diagnosis, besides the acquired brain injury, (ABI) and was worried that this may complicate matters. However, this is reflective of the fact that people’s lives are complex and a diagnosis of ABI does not preclude other health issues.

Analysis of Susan’s interview

Susan is in her fifties and lives in a rural town in the UK with her husband John. She had an established and successful career in nursing until about seven years ago when she acquired a brain injury from a sub-arachnoid haemorrhage. For some months afterwards she experienced extreme fatigue, facial paralysis, expressive dysphasia and sensory impairment of taste and smell (Headway, 2016b). This led her to be depressed in mood.

During her recovery she began to experience differing symptoms and sought medical help with this, only to be told that this was a delayed reaction the ABI.
Eventually she was diagnosed with Parkinson’s and was able to access medication to treat her symptoms and move her narrative forward again.

If Susan were to introduce herself to someone for the first time she would declare her nursing career and indicate that she was taking time out, ‘Erm, I would just tell them, probably how old I was, that I’m married, erm, I’ve had a career in nursing. Just out of nursing at the moment. I wouldn’t mention about what’s wrong with me or anything like that’ (3/8-12). This indicates that her nurse identity is very strong (Tajfel, 1978), having worked as a nurse for approximately thirty years. She also declares a pride in her achievements, ‘I’m proud of what I did and the hospice is still going so er, it’s nice that’ (1/14), suggesting an intrinsic reward from the helping and giving element (Csikszentmihalyi, 1990) and also that she has left a legacy for the future (Frankl, 2004). When she was still employed as a nurse and had been given her Parkinson’s diagnosis Susan began to consider that if she had to treat someone else with Parkinson’s that she would find this a difficult thing to do, ‘I think I would find it hard looking after people with Parkinson’s’ (2/782), suggesting that it would raise anxieties about her own future script and the person she may become, possibly requiring nursing care. She spent many years working with people in palliative care and had come to regard illness as only something that happened to other people, as she had always been fit and healthy prior to having an acquired brain injury. Working with people with the same diagnosis as herself would be a challenge to this healthy identity (Tajfel, 1978).

She would also be careful to protect her identity of being someone who had acquired a brain injury (Olney & Kim, 2001), possibly as this is not an identity she has fully accepted (Conneeley, 2012), or does not want to reveal this due to stigma or social acceptability (Goffman, 1963). Susan also identifies herself as not having a mother role (Hogg & Vaughan, 2014), ‘We don’t have any children’ (1/8), early in the narrative, identifying the social norm of someone her age usually being a mother at this stage of psychosocial development (Erikson, 1959).

Susan’s narrative tone is optimistic (McAdams, 1993). Her description of herself is independent and positive, reflecting optimistic qualities, ‘I’m a very independent person and I hope I’m a positive person as well and you’ve just got to get on with it haven’t you because it won’t be handed to you on a plate’
(3/940), also demonstrating her agentic approach to life (McAdams, 1993). With her secondary diagnosis of Parkinson’s Susan is adherent to advice offered by other health professionals, possibly due to her health background herself and in particular the advice about exercise as a therapy. It suggests she is keen to have a health locus of control (Sanders & Suls, 1982).

She talks very little about her life prior to having the ABI, giving no clue as to whether or not this optimistic tone is influenced by a happy childhood (McAdams, 1993). She does mention that she grew up in a northern town with her mother, father and younger sister. When she was sixteen she set out to fulfill her desire to enter the nursing profession. She was initially unsuccessful in her application but was determined to reach her goal, ‘got told to go away and I wasn’t nurse material. So I decided to prove them wrong’ (2/90), suggesting a determination and agency (McAdams, 1993).

She has some negative experience of the medical profession though this is far outweighed by her own positive engagement in healthcare services as a health worker. Following her recovery from the ABI she knew that she was still unwell but this was ignored by medics operating in a medical model of care (Bradby, 2012). Her husband intervened and a new GP came along and looked at her symptoms afresh. She was diagnosed with a second neurological condition, this time a degenerative one. This led to a period of depression and included personal difficulties due to her mother and father dying. However, she came through this with the help of medication and now looks positively to the future and being able to engage with some work that involves helping others. This suggests she began a period of progression recovering from the ABI, followed by a regressive episode before progressing in her narrative once more (Gergen & Gergen, 1986).

One demonstration of her optimistic narrative tone is by way of her reaction to engaging in social networking during her illness recovery. She found the negative or low achieving comments unhelpful, ‘I did it for a bit and then I was getting quite depressed actually cos people were putting things on like, ‘managed to get away without an afternoon’s sleep today’. I thought I don’t need this. It’s not me’ (3/804-806) (McAdams, 1993).
In terms of the structure of her narrative it appears to be progressive through childhood into adulthood (Gergen & Gergen, 1986). Her narrative continued to progress and she married John, who was a widower. She made a successful career out of the nursing profession, having to be persuaded at times to advance professionally but enjoying it when she did, ‘Er, not really interested into converting to be a registered nurse but a lot of people pushed me to do it and I don’t regret it actually.’ (1/12).

The main episode of regression in her narrative came when she had her brain haemorrhage, ‘and that’s when my life changed really’ (1/14). This was just over seven years ago and indicates the onset of biographical disruption (Charmaz, 1999). She was working in the community and came into the office to make a phone call. She had felt well, then strange. She then collapsed, ‘And the next thing I knew I was coming round on the floor.’ (1/14).

Whilst requiring health services, as opposed to being a giver of health services, Susan experienced a pattern of paternalism (Bradby, 2012) and her autonomy challenged. In hospital she had a fear of hearing bad news and avoided asking about her diagnosis and prognosis. This could be explained in terms of having fear of loosing her health locus of control, and holding a strong identity as a healthy person (Sanders & Suls, 1982). She was in denial when she heard the consultant discussing her diagnosis with his team and was shocked when realisation came, ‘Erm, and then he said to all his entourage, ‘this is Susan, blah, blah, blah. She’s had a sub-arachnoid haemorrhage.’ And I just felt like I’d had another one!’ (1/20). By stating that the hospital consultant had an ‘entourage’ (1/20), suggests that she believed he had a following of others that acknowledge his superiority and a hierarchical medical model of care. This was an initial episode of feeling depersonalised in hospital (Bradby, 2012).

The health and illness discourse is strong in Susan’s narrative, especially when she describes the identities she took on in hospital, ‘and then I became the subarach in the corner. That’s who I was. And then when I came back after the angiogram I was the failed embolisation. And I kept thinking ‘I do have a name!’” (2/355). This is a second example of depersonalisation and the resulting objectification of the healthcare system. However, with her nurse identity she admits that it was a mistake she had made herself in the past, ‘But then I thought, ‘I’ve done it meself’. On a ward you’re just another number really’
Susan was aware in hospital that some nursing staff avoided her and she identified with this avoidance behaviour as a nurse, possibly explained by social identity theory (Tajfel & Turner, 1979). She felt that some nursing staff avoided her because she was of the same profession as them, but now a patient, ‘I’ve probably done it meself. I found that some staff wouldn’t come near me. Some were all over me’ (1/26-28). She uses splitting to describe the type of nursing staff looking after her, by referring to the identity of some of the staff as, ‘the genuine ones’ (1/28) (Cashdan, 1999). This may reflect anxieties due to social identity and the nurses wanting to continue to identify with their professional role and not the patient role (Tajfel & Turner, 1979). She also felt that having a nurse identity impacted on how she was treated by different healthcare professionals. One registrar assumed she was knowledgeable about ABI because she was a MacMillan nurse and she had to correct him (2/405).

Her healthy identity was challenged when she asked hospital staff for a sick note and they offered her one for three months, saying that was just initially. She found this difficult to comprehend (Sanders & Suls, 1982). Because the nurse identity is so strong in Susan it may have led to a resistance to acknowledge the patient identity when she became ill, ‘Just don’t think things like that’ll happen to you. Particularly when you’re so well as well. You know, I was a healthy person’ (2/251-253) (Tajfel & Turner, 1979).

She was relieved to return home, finding sanctuary here. She did however feel as though she was forgotten about once discharged by the doctor, ‘He kind of said, ‘It’s happened, it’s been rectified, get on with your life” (2/504), suggesting that she experienced a lack of empathy from him (Bradby, 2012) and a lack of recognition of her biographical disruption (Charmaz, 1999). She suggests feeling let down by health services at this point, ‘But erm, you’ve to think about how people carry on at home really. I think if I’d had a bit more information I could have coped a bit better’ (2/1000-1004) (Kneafsey & Gawthrope, 2004).

She became exasperated at the lack of access to a consultant and felt that there was a lack of information for herself and her husband, ‘We eventually managed to get hold of some carer, patient leaflets about people who’d had a
subarachnoid haemorrhage erm, and that was a big, big, help’ (1/32). This additional understanding was important to them, possibly because knowledge of medical symptoms can help restore the health locus of control (Sanders & Suls, 1982). It was not only Susan that felt a loss of health locus of control, as she discusses her husband’s relief at gaining an understanding of the illness through patient leaflets, ‘and that was a big, big help. Cos especially for me husband. He kept reading through and saying, ‘Oh well that happens to you, when you experience that’’ (1/32). She emphasises her husband’s reaction to her ABI by stating that he was, ‘devastated’ (1/26) and reacted badly to it (Medved & Brockmeier, 2008). She explains that this because his first wife died of an ABI some years previously, which increased his fear when she became ill. Having unexplained symptoms led to stress and low mood, ‘I think if someone had explained how tired I would have been, I think that would have been a big, big help. Cos it’s quite frightening.’ (1/32). She draws on metaphor to explain the enormity of the fatigue symptoms, ‘Getting dressed was like climbing Everest’ (1/44) (Berger & Luckmann, 1966; Willig, 1999).

Once discharged from hospital she became aware of her residual symptoms, such as some facial paralysis and sensory loss regarding taste and smell (Headway, 2016b). She also became embarrassed and frightened at the effects of fatigue, ‘Cos sometimes things I was saying, (laughs), utter rubbish which I was, got quite embarrassed about really.’ (1/72-74). This was a fear that she had no control over normal bodily function (Sanders & Suls, 1982). She became conscious of the facial paralysis, possibly due to stigma (Goffman, 1963). The main impact on function was being unable to drive.

She has always been very fond of dogs and was very close to her last pet during her initial biographical disruption. She regarded her pet as being able to sense when she was ill and it was very protective of her during her recovery phase from the ABI. Susan always had a close relationship with her dog and found her dog’s reaction to her illness strange, in that she kept her distance from her but seemed protective at the same time, ‘she’d always be sat there and she see me downstairs’ (2/66). This could be understood as a form of social capital by way of taking comfort in her pet (Bourdieu, 1986).

She began to increase her daily activities. Over time her symptoms began to improve and she returned to part-time nursing, which she enjoyed. Her narrative
becomes progressive again for a time (Gergen & Gergen, 1986). She completed a degree programme and celebrated her success at the graduation. She struggled with the working demands, especially the physical demands and travelling.

Returning to her nurse role at work caused some stigma related issues, possibly due to her illness affecting her brain and assumptions being made by work colleagues, ‘they don’t treat you different but I don’t know, they look at you. It’s strange, cos I think they think “brain related!”’ (2/516-518) (Goffman, 1963; Tajfel & Turner, 1979). She didn’t mind being seen in public as different, (her head had partly been shaved), indicating that she had a physical illness, but she disliked having the facial paralysis of not being able to move one eyebrow, ‘Erm, that didn’t bother me really. But I suppose you did look a bit different.’ (2/530). This suggests that there is a social acceptability around a physical illness that requires hair shaving but loosing control over a part of the body carries stigma of loss of control (Goffman, 1963).

She did however have some reactions from colleagues that were the reverse, for example a colleague who had previously not been friendly but had had an illness herself now took time with her, which may have been due to social identity issues (Tajfel & Turner, 1979). A medic colleague took time to do some enquiry on her medical condition and offered help, which she felt demonstrated care and compassion.

Then work became difficult to manage and she began to experience further symptoms, ‘I enjoyed it. Erm, but by August last year, the symptoms had got a lot worse. I was developing a bit of a tremor in my arm. All still down my right side. Horrendous fatigue.’ (1/44). This was to be the onset of a second neurological condition and thus a regressive episode began (Gergen & Gergen, 1986).

She had a difficult time getting her GP to acknowledge that her new symptoms were not associated with her ABI. She became despondent about his response, ‘You think you know I’ve been a nurse, and all the times I’ve helped people, and you do know when there’s something wrong with you. You do.’ (1/72). This seems to indicate that she was disappointed that her nurse identity was not acknowledged by the GP, as well as her dedication to helping people: now she
was not receiving help when she required it herself (Tajfel & Turner, 1979). His paternalistic response was to suggest that her behaviour was psychological, (Bradby, 2012).

However, she eventually accessed a neurologist who diagnosed Parkinson’s. Because her GP had failed to acknowledge her symptoms for some time. He eventually offered an apology, ‘and sorry, sorry, he said afterwards when he’d examined me, straight away he felt it was 100% I’ve got Parkinson’s disease.’ (1/48). Her GP decided to prescribe her anti-depressant medication, to try and minimise a negative reaction to another loss of health locus of control (Sanders & Suls, 1982), ‘In the meantime, before I’d seen the neurologist, the GP did put me on anti-depressants. Was very hard on those, just getting over the initial two or three weeks.’ (1/50). ‘When I look at a few years ago, I never thought I’d be on anti-depressants or anything like that but they were a life saver.’ (1/56).

Susan’s reference to her being in receipt of medication for low mood symptoms suggests that she stigmatises mental health issues (Goffman, 1963), or it could be another example of her strong healthy identity (Sanders & Suls, 1982).

Obtaining a diagnosis made a significant impact on her life as she could now be prescribed the correct medication, ‘Erm, and within two, within a week of taking medication all the symptoms were gone. Incredible!’ (1/50). Once she was given her second diagnosis she re-evaluated her pattern of daily activities, such as her work – life balance, ‘I thought, I don’t wanna be working till I’m sixty five. I wanna reduce me hours a bit so. It wasn’t, it was partly because I was feeling very tired, but I just, you know there’s more to life than work all the time so…’ (2/646-648) (Christiansen & Matuska, 2006).

However, Susan has always helped people by way of her nursing career and now that she currently does not work as a nurse she still has this desire to help people. She is currently structuring her life post-diagnosis by continuing with an occupational persistence or habituation of drawing on her nurse identity (Kielhofner, 2008). Her friends had often told her that she would make a good counselor so she has begun a counseling course and would like to volunteer using these skills, though no longer in an area of palliative care or bereavement, which was her nursing specialty. She does miss her nurse role and the intrinsic reward that the work brings, ‘you are needed by people and giving them a lot of advice and help. And then that’s what I enjoyed and then all of a sudden that’s

452
taken from me really.’ (3/1010-1012) (Csikszentmihalyi, 1990). This suggests that losing her occupational identity has had an impact on her (Christiansen, 1999). Becoming a volunteer may go part way to re-establishing a nurse identity (or at least a helping identity) and may improve her self esteem, ‘Get a bit more self-esteem back.’ (2/810). Re-establishing a routine is also something that Susan considers important, which relates to temporal adaptation following a life change (Christiansen, 2000).

She acknowledges that her being ill had a large impact on her partner in that he was very worried and that this was exaggerated by the fact that his first wife had died under similar circumstances (Charmaz, 1999). Some years later when she had depression Susan felt that this too had an impact on him, in that he didn’t know how to support her at this time, ‘His answer was, let’s go on holiday, but I said ‘it doesn’t go away, it comes with me’” (3/844-846). This indicates that there is also a carer’s loss of health locus of control, which can cause stress or anxiety (Sanders & Suls, 1982). The experience of having the ABI has strengthened the marital relationship, ‘Erm, I think since I’ve had the haemorrhage it’s brought us a lot closer. I think it does one way or the other.’ (2/8-10) (Folkman & Moskovitz, 2000).

She valued the support from friends during her recovery, ‘And a friend would take me out in the car, have a coffee and things like that.’ (2/455), demonstrating the importance of social capital in recovery (Bourdieu, 1986). She sees herself as sociable and the illness experience has shown her who her true friends are. Several friends have been very supportive and understood when she no longer wanted to socialise at times. They supported her husband by driving him to the hospital when she was ill, as he couldn’t drive. She enjoys being in groups, being it to meet for coffee or for exercising and thinks that she wouldn’t do this kind of activity if alone. She enjoys walking, swimming and going to the cinema. There is an element in her narrative of some people not coping well with her new identity of being an ill person, ‘found it difficult to deal with.’ (2/548) which is a potential social identity issue (Tajfel & Turner, 1979). This has been particularly an issue for her sister who is her closest family member.

Susan talks about what being a dog owner means to her, especially during her time around the ABI. ‘Er, in between dogs at the moment. Big dog lovers.’ (1/8).
She found her dog to be a supportive help during her recovery and indicates that her dog was trying to understand what had happened to her, ‘and she would sit on one side and just stare at me head where they, where they'd shaved it and I had a dressing. She’d just stare at that all the time.’ (2/64). Susan may be indicating that she experienced a supportive or emotional connection with her pet, perhaps in the absence of children. She also discusses the therapeutic element of having a pet and how it increases social contact, ‘People with dogs stop and talk to you.’ (3/504), which suggests the social group identity element of being a dog owner (Tajfel & Turner, 1979). Susan and her husband lost the motivation to holiday abroad since Susan became ill, fearful of her being taken ill whilst abroad. This could be due to fear of loss of health locus of control (Sanders & Suls, 1982). A successful compromise has been to buy a static caravan a few hours drive from home, close to a beach in a picturesque spot. Susan suggests a happy ending to the holiday and the dog owner narrative when she discusses getting a dog to replace her lost companion, ‘Yeah, we will now we’ve got the caravan. Yeah, doesn’t feel right on the beach without one.’ (3/100-106).

Susan enjoys creating a pleasant environment in her garden, to then be able to relax in. Her motivation to do this was lost when she had her secondary diagnosis but has now returned, ‘This is about the best year we’ve had with plants really. I wasn’t all that bothered last year but this year I have been.’ (3/286), indicating how low mood can impact on motivation to engage with activities. Some of her other typical home activities were also affected such as cooking, further impacted by fatigue (Headway, 2016b).

Susan relates a difference in the community support services for the two diagnoses she has had. Little support appeared to be available for her ABI and this led to difficulties in coping. However, with her diagnosis of Parkinson’s she has been offered a significant amount of support, ‘I found the support after that was fantastic. The Neurosurgeon, sorry the Neurologist made it quite clear that if I had any problems I was to ring him. And he’s the type of person that I feel I could do that.’ (1/56). This is in stark contrast to the support she received after her ABI (Kneafsey & Gawthrope, 2004).

There are still moments in discourse when her nurse identity, even though she no longer works as a nurse, comes out in the open overtly, ‘I’ve given so much
to me job. I love me job. I really did.’ (2/902), slipping between past and present tenses. This indicates that she carries strands of the former identity forward into the present (Nochi, 1998; Gelech & Dejardins, 2010).

Susan looks back on her experience by viewing life differently. She never used to understand her patients who lived for the present day only, but now she can understand this, ‘It’s easy to say that but I always used to think, I think it would take something really dramatic to me or someone close to me, for me to initiate changes like that and it does.’ (1/60). Today she lives much more in present time, as opposed to the future. She also expresses an acceptance of faith and that her life is controlled by a higher order, ‘Things meant to happen for a reason.’ (2/42) (Strom, 2014).
Appendix S: Analysis of narrative

Participant 6 – Hilary – A chaos narrative

Positional aspects of Hilary’s narrative interview

Hilary was a similar age to myself and had children of a similar age. She talked at length about a geographical area where she had lived that I was very familiar with too. Yet I was struck by how different our lives were, not just because of the ABI but also due to life choices made along the way.

I found her story took me on an emotional rollercoaster, because of the extreme circumstances she had coped with over the years. Hilary appeared to be a very capable and determined person, yet had been faced with very little support at times when she had been very vulnerable. There was also a lot of information about her life to take in to try and make an initial coherent story, which made me liken it to Frank’s description of a ‘chaos narrative’ (Frank, 1995) due to either the narrative’s current position in terms of any resolution to the biographical disruption or Hilary’s cognitive deficits.

Hilary was obviously very intelligent yet I doubted at times, if the extent of her brain injury made her a suitable participant, as there were occasions where she strayed off the conversation topic. She did give detailed information of her life story but this straying did happen on a number of occasions.

Analysis of Hilary’s interview

Hilary is a fifty three year old woman who lives alone in a local authority bungalow, in a rural village. She had a brain haemorrhage approximately ten years ago and is still making progress with daily living. Her symptoms include issues with short-term memory, executive functioning, dyscalculia and mobility and balance (BSRM&RCP, 2003; Headway, 2016b). She has several hours of care support a week, from a private rehabilitation company. This suits her needs much better than the statutory care support, as things are done with her, rather than to her with this package. She is divorced and has two sons in their late teens / early twenties. She has a strained relationship with them.
Hilary’s narrative tone is primarily optimistic (McAdams, 1993). When she talks about her early life it is full of declarations of achievement in terms of learning to talk, read, swim and write music from an earlier than average age. Her family moved around with her father’s work and she appears proud to have lived in different countries and speak different languages, both as a result of this and being intelligent. She promotes an image of a happy childhood with her parents and brother, which may account for her optimistic narrative tone (McAdams, 1993).

The optimistic tone pervades her story when she reflects on how her ABI occurred. She sees her ABI as possibly being the result of not having had early intervention in hospital, but declares she wouldn’t seek compensation as she has worked in hospitals and recognises human factors in the workplace (Reason, 1995). She notes small improvements in her abilities over longer periods of time and sees this as slowly relearning the capacity she has lost through the ABI, as opposed to dwelling on her loss of functional ability, a form of positive thinking (Scheier & Carver, 1993). She is keen to receive the kind of help that leads to her learning, as opposed to having things done for her i.e. rehabilitation versus care. When services fail to meet her needs she is circumspect and tries to see how the system is failing e.g. staff being paid low wages does not promote caring and dedication.

She has an interest in history and politics. She reflects an optimistic tone when she tries to make a difference by, for example, being involved in the start-up of a new branch of a head injury charity or taking part in research, so as others following behind her may have a better life (McAdams, 1993). Formally, she was the one who gave advice in her own career and coming to terms with now being the one who receives it, which reflects a consideration of a new personal identity (Hogg, Terry & White, 1995) However, she can’t understand where the person she was in the past went to and in part still feels like that person, suggesting the importance of acknowledging strands of the former identity for individuals who have undergone biographical disruption (Nochi, 1998b). Her key message to others who experience functional limitations as a result of ABI is a positive one, ‘I would advise anyone trying to relearn anything, to just nibble away at it. Some things were initially comes in leaps and bounds and now this is ten years and
I'm still learning' (3/1629-1633). This exemplifies her overall optimistic tone (McAdams, 1993).

The structure of Hilary's narrative very much begins as progressive (Geregen & Gergen, 1986). Hilary had a happy childhood and experienced many development opportunities as a child, such as learning languages, music and enjoying sport. Some of this time was spent overseas in a privileged household with servants, then she returned to the UK for senior school. She promotes an identity of being intelligent and of high status, 'I always had a high IQ and I was always in the top group at school.' (1/21). She gives an image of her childhood being special and different from a typical UK childhood, 'We had peach trees. We had apricots, a grapevine, we didn't go under the grapevine cos it was full of poison spiders' (2/39). She emphasises her privileged position as a child when she discusses being segregated from other children, 'My Dad would never let me play with children from the council estate when I was growing up.' (1/25).

Her progressive narrative continued and she broke gender stereotypes as a young person, by such as riding a motorbike and forging an independent career. She took opportunities in the beautiful rural surroundings of where she grew up and learnt new skills and engaged with numerous recreational activities that many young people don't have opportunity to do. 'I've, songs I've written have been played on the radio and this kind of things.' (2/1627-1629). This account of herself as a young adult is as someone who expresses agency and is empowered (McAdams, 1993). Her educational achievements across a broad spectrum of disciplines, such as art, law and psychology, are also emphasized in her narrative.

Hilary may feel the need to present herself as being someone as skilled and achieving in the past as it is the converse of her life as it is in the present. This could be explained in terms of social identity and the groups with which she identifies (Tajfel, 1978). She may not wish to be identified as someone who is deskilled and disabled and so strongly projects her former identity to compensate, as a reaction formation defence mechanism (Freud, 1946). It may be that her current loss of self-esteem moves her to promote a time in her life when she was more able. It is also reflected in her reduced empowerment in present day circumstances.
Hilary declares early in her narrative that she went in to pharmacy as it involved helping people, (which later becomes an occupational persistence or habituation through her narrative), ‘I didn’t want to be an English teacher. That was my Mum’s dream. I wanted to help people’ (1/14) (Kielhofner, 2008). She declares that nursing was too distressing for her and that pharmacy offered a more suitable role for her, ‘I cared, too much really. I got, made a connection, whereas pharmacy, you’re still helping.’ (2/351-355).

Her narrative becomes regressive when she talks about her unsuccessful marriage (Gergen & Gergen, 1986). This led to discontinuity in her role of mother. She gives multiple examples of being treated unfairly, abused and rejected. She describes her first husband as undermining her self-esteem, ‘But by the time I got away from him, I wouldn’t even raise my head. And it’s astonishing, I mean, that somebody who could have been as strong as I was, if somebody’s telling you that you were rubbish and you’re rubbish all the time, you believe it.’ (2/435-437). At one point in the narrative she suggests an identity of being labeled as long-term mentally ill, having had an episode of puerperal psychosis. This led to her being disbelieved when she tried to report her husband’s physical abuse, ‘So when he said I was imagining it, people obviously believed it.’ (2/441).

Hilary has several examples of poor relationships, which affect her current situation. She now describes her first husband as, ‘the wrong man’ (1/12). Her choice of words to describe the end of the relationship indicates disempowerment, ‘Eventually they got me out.’ (1/12)(Berger & Luckmann, 1966; Willig, 1999). She feels that one of her sons has learnt behaviour from his father’s physical abuse of her and her son has been violent towards her also (Bandura, 1977). Within the family her father transfers blame to Hilary for being the cause of her mother’s ill health, which was brought on by stress. This causes a strain in her relationship with her parents and she carries guilt for it too.

The regressive trajectory continues in her narrative (Gergen & Gergen, 1986). She met another partner who initially formed a good relationship with her until she experienced her ABI, ‘But then I met someone else who seemed okay until I didn’t recover from the brain hemorrhage.’ (2/475-477). This was the main incidence of biographical disruption (Charmaz, 1999). When Hilary had initial
balance problems due to the ABI her partner found it more socially acceptable to let his family believe that she was intoxicated, rather than she had a disability, 'And I couldn’t walk in a straight line down the aisle. And he told everybody I was drunk!' (2/624-626). This suggests the enormity of the stigma attached to disability (Goffman, 1963). Her relationship with her second partner broke down and she discusses the lack of support she was given and then left at her parents, with no access to her house or belongings, ‘and a year after that I wasn’t fully recovered and he took me to my parents for the weekend and left me there.’ (1/12). Again, this suggests her feeling disempowered in the relationship.

There was an epiphany moment when Hilary was first discharged from hospital: she had been unaware of why she could no longer function properly. She talks about the value of healthcare professionals helping with service users understanding of their symptoms, ‘I couldn’t understand why. I didn’t know what I was there for. And then she explained that it was retention and like short term memory it was like a light bulb coming on and I trusted her after that.’ (1/21). This demonstrates the importance of empowerment through informing patients about their illness and the psychological difference this can make, often neglected in a medical model of care (Bradby, 2012).

Hilary mentions that following her brain injury, ‘I had to learn to lie.’ (2/485). This is due her becoming disinhibited in her speech and it affecting her social interaction and thus relationships (Headway, 2016b). She made little progress with her functioning and experienced a further regressive episode when her partner took her to her parents for the weekend with no intention of returning for her. At this point she looked to statutory services to find her a place to live or any form of help to progress her narrative.

Services she has been directed to have often been wholly inadequate for her, such as a mental health ward and an elderly care home for people with dementia, due to there being no specialist head injury services, ‘And it was the brain so they put you in the psychiatric hospital which can be quite scary. Erm, particularly when the staff nurse used to mock when I was trying to talk.’ (3/1363-1367). She exemplifies the inappropriate placement she endured in an elderly care home when she states, ‘I mean, I was in between a guy who they had to call the police to and a paedophile (laughs)’ (1/18). Hilary draws on
metaphor to suggest that whilst in a care home the level of understanding of the care home staff was very low, ‘Minimum wage, pay peanuts you get monkeys you know.’ (1/18), displaying irony in the narrative (Frye, 1957).

‘Er, but the, in all, the care that I got offered, you know you’re supposed to get a choice of care. I got no choice.’ (2/743). This is an indication of the lack of appropriate statutory services for middle-aged adults with ABI. Currently she describes being ‘terrified’ of returning to a similar place as she found it stressful, (1/18). However, whilst in the care home for elderly people with dementia she did demonstrate a degree of agency by taking on a role as a steering committee member for a new Headway group, ‘I helped set up the Headway group in the area.’ (1/18) (McAdmams, 1993). This is also an habituation of helping within the narrative (Kielhofner, 2008).

She was placed inappropriately for two years and then was asked to leave due to a funding shortfall. She was offered little assistance to find a place to live, ‘I was supposed to find me own house. Now I didn’t know how. Erm, me Mam and Dad had called the Carers’ Association and they helped.’ (2/735-741). This suggests a lack of tailored support and understanding of her functional difficulties by statutory services. It was charity support that helped her when statutory services were inadequate.

On moving to independent social housing accommodation her narrative begins to become progressive again (Gergen & Gergen, 1986). However she continued to experience disempowerment when she was not allowed to administer her own finances, ‘Social services took my bank account off me, didn’t give me any money for food!’ (1/21). She had two house moves and is now in a smaller home, which can’t accommodate her sons, ‘I’ve moved because of the bedroom tax and I’ve lost track of the address.’ (1/20). Her executive functioning difficulties are such that she is unable to track information such as where her sons are now living as young adults (BSRM&RCP, 2003; Headway, 2016b).

Today Hilary’s narrative is slowly progressive (Gergen & Gergen, 1986). However she feels that her feminine identity is challenged by her hair loss, ‘It, it, you feel naked. A bald man is attractive but a bald woman is a freak!’ (2/1014-1016) (Tajfel, 1978). She considers the hair loss to be due to stress, caused by her continual worry over living with changes to the benefit system. The
embarrassment of hair loss limits her occupational participation in her hobby of swimming, exacerbated by her sequencing problems for dressing in a public place, without her cue cards (Headway, 2016b).

At the present time Hilary is trying to relearn to play the guitar and a number of other activities, ‘But the guitar I’m trying to relearn. I think it’s the fact that I now have to think about it. It’s the same with the walking. You don’t usually think lift leg move forwards, you just do it. It’s like trying to get washed. I couldn’t think why I couldn’t fill the sink initially.’ (1/24). She also uses cue cards for several activities, ‘I’ve got cards for most things. They’re useful.’ (1/24). This indicates that activities involving sequencing are now difficult for her, due to impairment in executive functioning (BSRM&RCP, 2003; Headway, 2016b). Progress is slow but does continue, ‘I mean I don’t need instructions pretty for making a cup of tea now.’ (2/1143). It has been important to Hilary to still be able to attempt activities rather than to be cared for, ‘I didn’t, didn’t need everything done. I just need telling how to do it.’ (2/753), reflecting a rejection of a sick role identity and a desire to relearn and move towards independence (Sanders & Suls, 1992).

Hilary does continue to move herself to her zone of engagement with some of the activities she engages in (Vygotsky, 1978), such as the activities weekend organised by the brain injury charity, ‘Erm, I would really recommend it. It does wonders for your self confidence.’ (2/946). This is an example of how she is keen to relearn and improve her current situation. She attempts self-rehabilitation through social networking games such as Farmville. She is forward-looking in seeing the internet as a valuable resource and so is motivated to learn IT skills. She also enjoys the escapism of reading fantasy novels ‘Escape. It’s harming nobody.’ (3/891-893).

As Hilary lives alone and has mobility issues public transport is important to her. She does not view her village as rural, as it has good transport links to the local town and city. However, she is unable to manage the journey to visit her parents, due to access issues with different railway platforms and the change of train required. Also, her parents live in an isolated location, enhancing the logistical difficulties. The village suits her needs from the point of view of it being predominantly flat, making mobility easier. Being known in the community is important to her, as now she feels people know that she requires extra time and has special needs. (This was not always the case as in her early days her
balance issues and slurred speech were yet again misunderstood for intoxication and she was refused entry onto buses.) Living with short term memory issues means that she regularly forgets items of food shopping and living close to a shop, (where the shopkeepers also understand her dyscalculia), is helpful in that it is open for long hours for repeat visits (Headway, 2016b). She is appreciative of the social capital in having a local police service where the officers know who she is if she is locked out of her etc. (Bourdieu, 1986).

Hilary now forms an identity of being persistent and resilient, ‘Persistence. I think some of what I’ve done is through sheer stubbornness really.’ (Sanders & Suls, 1992). This is supported by her discourse around her reluctance to adopt an identity of being unemployed in the past, ‘I wouldn’t sign on I’d take three part time jobs rather than sign on.’ (2/453). This is another example of her rejection of a sick role and illness identity (Parsons, 1975).

Despite a number of failed relationships in her life Hilary does find comfort in her cat, ‘You need something you can have a sort of relationship with.’ (3/733) Her cat does give her a form of social support, ‘I, living alone, well apart from (cat’s name), you get quite isolated sometimes.’ (3/1779) (Maslow, 1943; Bourdieu, 1986).

Hilary exhibits social responsibility and civic engagement by her interest in politics and voting. She follows her local MP through the Parliamentary debates on the internet, ‘It’s it’s debate and it you click on there, it tells you what everybody says.’ (3/546-548). Her occupational persistence or habituation of helping is reflected in participation in the research, ‘It’s why I’m doing this because examples could stop it happening to somebody else or maybe go someway towards it.’ (2/ 812-818) (Kielhofner, 2008).

Hilary mourns the loss of an occupational identity in terms of a profession or paid employment (Christiansen, 2000) and raises this as an issue, ‘It’s natural isn’t it, if somebody says, “What do you do?” When you meet someone it’s one of the first things you say. “What do you do?” What can I say? (laughs). You know. Work it’s I don’t know whether I was brought up by this, but your work is your identity and it’s important.’ (3/1243-1251). This can be explained in terms of social categorisation (Turner, Hogg, Oakes, Reicher & Wetherell, 1987).
Lack of understanding from statutory service employees and modes of communication have caused frustration. With agencies becoming more automated it presents Hilary with challenges to dealing with them effectively, 'I can’t stand up and hold a conversation on the phone and write.' (2/1129). Understanding information in the format by which it is communicated, is also a challenge, ‘The housing association don’t write to you. They send you a magazine, so you gotta pick the information out of that. It’s in with a lot of it’s hard.’ (2/1435-1437). Both of these are examples of how executive functioning is a requirement of modern civic life, by way of needing to process complex information.

She has been disempowered by circumstances where her ABI symptoms have been misunderstood. Disbelief of her ABI has been experienced due to her unsteady gait, creating an impression that she is intoxicated, which she found hurtful, 'It’s quite hurtful. My Dad didn’t believe me you know....that people were saying I was drunk.' (1/20). People often believe that she is disingenuous in having brain injury symptoms, as her disabling features are so localised e.g. she can express vast knowledge but struggles with sequencing, counting and reciting the alphabet. Conversely other aspects of her ABI dysfunction remain hidden and sometimes her abilities are over-estimated, ‘Communication is important but unfortunately I give the impression (coughs) that I can do things that I can’t yet.’ (1/14). It is not uncommon for people to find distress in their having a non-visible disability (Olney & Kim, 2001). This can cause a lack of understanding in shops when she is unable to calculate payment for goods, ‘Sometimes I wish there was actually something that people could see.’ (1/24).

Hilary uses metaphors to explain her situation, such as feeling like being behind a glass wall and life being like climbing a ladder with some of the rungs missing. (Berger & Luckmann, 1966; Willig, 1999). Hilary still carries the identity of her pre-injury self, 'You know, but I used to fell walk and this kind of thing. So it’s frustrating not to be able to, because in my head I can do these things!' (3/2004-2008). This is common in people with ABI and it has been found that it is important for the pre-injury self to be acknowledged by others, as opposed to simply seeing a now-brain injured individual (Nochi, 1998b; Conneeley, 2012).
Appendix S: Analysis of narrative

Participant 7 – Helen – A wife and carer’s story

Positional aspects of Helen’s narrative interview

Before the first interview I was aware that Helen was a nurse and wondered if she had any professional pre-conceptions about my being an occupational therapist. Helen was one of the few participants that exhibited an awareness of my professional background and appeared to discuss her interactions with other occupational therapists positively.

Helen shared some very personal issues with me about her marriage and her existential being and I had to think carefully about this not influencing me to only present her in a positive light, as I was touched by her openness to engage with me. I was also conscious of the fact that Helen had a number of similarities to myself e.g. health worker, similar age and similar family status. For this reason I had to read more carefully into her discourse so as not to make assumptions from my own personal experience.

Analysis of Helen’s narrative

Helen is in her mid-forties and lives in a UK village with her husband Dave and pre-teen son and daughter, Tom and Emily. Helen and Dave have been married for over twenty years. Helen’s relationship with Dave is the only partner relationship she has known. They live in a private house. Helen works full time as a nurse. Dave was in the merchant navy then a nursery nurse, until he had a cerebral vascular accident, (or stroke), four years ago. He has not worked since. He has cognitive symptoms as a result of this ABI, including visual, organisational and memory issues and being unable to read, due to the specific site of the brain lesion. He also has seizures. Depression is a result of Dave’s biographical disruption.

Helen’s story appears to be a mixture of both optimistic and pessimistic narrative tone, with neither one predominating, thus probably objective. She describes her parents as rarely showing emotion as she grew up and she held a
romantic notion of having a ‘cuddly’ father, which never materialised. Overall she indicates that her developmental years were satisfactory or unremarkable, which may influence her stable narrative today (McAdams, 1993).

Helen sees her husband as the only man who has filled the partner role in her life, demonstrating the commitment through longevity, ‘the first proper real boyfriend’ (2/32). Helen sees biographical disruption, such as ABI, having the potential to be an awakening for an individual in that altruistic traits or an appreciation of life may be realised as a result (Babula, 2013). However, this has not come to fruition in her relationship with her husband, which she sees as a disappointing result of the ABI. This appears to be a romantic form of story, which has fallen short of expectations (Frye, 1957). It has changed her life for the better in some aspects however, in that she now takes on roles of responsibility in the marriage that she previously left to her husband, such as being the organiser and learning to cook, thus being developmental for her (Dewey, 1938; Grant, Ramcharan, McGrath, Nolan & Kready, 1998). Her children now have a first hand appreciation of what life can be like for someone with a disability, which she is pleased about, in terms of their personal growth and development (Grant, Ramcharan, McGrath, Nolan & Kready, 1998). She believes that her father is proud of how she manages her life, which gives her comfort and also by receiving acknowledgement from Dave’s family for the adversity she experiences in her relationship.

The experience has also given her the opportunity to meet people she otherwise wouldn’t have met, who have given her support, such as through the brain injury charity and she values these relationships, which indicates the value of social capital to coping (Bourdieu, 1986). She has also undertaken activities she wouldn’t have done otherwise, which have helped in her personal growth, such as zip wire challenges ‘Well it has changed my life. Yeah. Yeah. I’ve met people I wouldn’t have met’ (3/1034), ‘But yes, it has been good’ (3/1043).

Helen reflects a stable narrative growing up, in that she had a stable family environment, but saw little of her father due to his work arrangements (Gergen & Gergen, 1986). She reflects progression when she moved to undertake her nurse training, close to Dave (her pen-friend at the time) and then in marrying him. Stability ensued when she accompanied Dave on some of his trips abroad, him being a cook in the merchant navy. Him taking work on land enabled a
progression in the narrative by being the correct time to begin a family (Gergen & Gergen, 1986).

The stability continued until the event of Dave’s brain injury and the past few years have meant trying to establish a progressive narrative from this low point to reach stability again (Gergen & Gergen, 1986). She describes her relationship with her husband as the only partner relationship that she has had. She holds Dave in admiration in terms of his intelligence and being a good father. Helen sees her husband as essentially the same person with some aspects changed, rather than a public held perception of someone now becoming excluded from the non-disabled hegemony, once acquiring a significant disability (Goodley, Hughes & Davis, 2012). Helen presents photographs of her and Dave in romantic pose, reflecting the affectionate element of their relationship. The progress of her husband’s occupational performance, even if minor, is acknowledged and she is dismayed when health professionals fail to praise this and dwell on the negative aspects.

She takes care to protect him from making his cognitive inadequacies overt, such as his declarations that something is new or has changed when in actual fact it isn’t or has been like that for some time. This is an extension of her nursing traits of encouraging and being supportive (Lindberg, Kruszewski & Hunter, 1998).

Pessimistic tone is expressed when she hoped for more support from statutory services at the time of Dave’s ABI, ‘And nobody, nobody tells you anything’ (2/204) (McAdams, 1993). During this period she struggled to cope, ‘And I’m sitting there thinking oh god I can’t bear this’ (2/229) (Anderson et al, 2009). Helen’s psychological reaction to Dave’s trauma was that she became hyperactive trying to control the situation ‘I was as high as a kite but always knew exactly what was going on and I could talk a thousand miles an hour’ (1/19). Her friend described her coping as amazing, but she knew that she wasn’t. Helen anchors her initial reaction to Dave coming out of hospital post-injury as being fearful of coping, ‘I was beside meself really’ (1/18) and ‘I would just gut the house. I would put every single little piece of toy back where it should be and it would be like, wow, this is great’ (2/238). This represents trying to regain control of a difficult coping situation (Burger & Copper, 1979).
There was an obvious role strain with now being the organiser of a family at home and less contribution of parental responsibilities from Dave, (Mauzer & Richer, 1998). This impacted on her work performance, ‘And I have struggled… I was told I wasn’t getting things done. But I never found out what’ (2/671-673), (Martin, 2012). She objectifies coping post-injury to a fight, ‘I sort of spent four years quietly battling it out’ (1/19) (Berger & Luckmann, 1986). Within this period she gives a regressive description of events that should be pleasurable, such as family holidays, ‘and even things like that, you wouldn’t realise would be a trauma’ (1/29).

In terms of her current personal being she does express some elements of regression, ‘Er, I sometimes, I just wish I could sort of hibernate’ (3/1784) (Gergen & Gergen, 1986). She is frustrated at people not understanding that Dave has an invisible disability and, for example requires more time in shops with his reduced occupational performance capacity, ‘And the assistant was horrible’ (2/435) (Olney & Kim, 2001). She has reacted to this by becoming agentic and undertaking elements of a quest narrative to educate people about the needs of others with disability, writing to the manager pointing this out and suggesting to herself that she could do more along those lines with such as campaigning (McAdams, 1993). She feels she should do more in this advocacy role, to campaign, feeling a sense of injustice, ‘sometimes I feel I should be on the telly, saying, campaigning or something you know’ (2/341).

The caring and rehabilitative aspects of the nurse role spill over into her approach and expectations of living with a husband who has an acquired brain injury. Helen attributes the dog as the main support for Dave, immediately following Dave’s ABI ‘The dog was what got him through. Not me unfortunately’ (1/19) and she admits to being jealous of the dog because of this, perhaps because she wanted to be fulfill a need to be the heroine in what could be a romantic narrative where adversity is overcome (Frye, 1957).

Her immediate response was to try and be the one who rehabilitated him, ‘so cos I envisioned sort of taking months off work and helping him’ (1/29) before appreciating the role conflict here (Martin, 2012; Heward, Molineux & Gough, 2013). She dismissed his acceptance of being at home without work, occupation or clear focus. ‘Erm, but I just wanted to find him something like I say, I looked at
xxxxx (local museum) whether he could volunteer there in the background’, (3/1487). This led her to seek out a number of unsuccessful volunteer posts for Dave. This is akin to a work ethic where the belief is that one can’t be happy and unproductive. Being at home unoccupied could be anchored in the social representation of work versus non-work (de Botton, 2009). Helen expressed agency through attempting to find vocational activity for him. Her keenness to have Dave active during the day is almost from a rehabilitative perspective in terms of her nursing occupational persistence and habituation (Kielhofner, 2008) and thus includes images of him at his college in the photographs, ‘All I wanted was for someone to get him out of the house’ (2/32). Additionally it may be viewed as necessary to her for her husband’s identity with a traditional male partner and breadwinner role, ‘it’s a man thing to be able to drive. To be able to work’ (3/1479). She does represent him as being agentic in the stable elements of the narrative when she discusses his role as father, ‘very hands on and he pushes the homework’ (3/166-168) (McAdams, 1993).

There is an habituation in Helen’s narrative linked to the nursing role and helping people, ‘it’s something to help people and that’s what I’m about really’, (3/1111) (Kielhofner, 2008). She worries about his health and welfare when she is at work in the nurse role and he is at home and may require assistance with some aspects of his occupational performance, such as self-medication. She also worries that he may have another stroke and the fact that he has suicidal tendencies due to depression. The role conflict does sometimes interfere in the relationship when Dave declares, ‘You’ve always got your nurses hat on’ (2/299). However, she does see being a nurse as a way of coping over the past few years though, in that it gives her a better understanding of Dave’s situation, ‘And I think if I hadn’t been a nurse, I probably wouldn’t have stuck it’ (1/19) and ‘I knew he wasn’t going to kill himself even so. I suppose that’s being a nurse’ (1/22), (Kielhofner, 2008).

This nursing/caring is linked to making a difference in people’s lives, which Helen tries to do when she attends the charity meetings and welcomes people. She also thinks she should be more of an advocate for people with disabilities and felt very pleased when she wrote to complain about how Dave was treated by shop staff. This is similar to how Frank would describe the person with a quest narrative, having overcome adversity and now wanting to make a difference for others (Frank, 1995).
She is more satisfied now that there is provision for a paid carer to do things with him each week. She welcomes his recent enrolment at a college on a pre-work programme, even though she sees his future as a worker as unrealistic, which has given stability to this aspect of her concern about him being unproductive. Her experiences have made her consider her professional boundaries at work and she takes care not to disclose to patients’ relatives when tempted. It has also made her be more empathetic to patients’ relatives, now she realises that they have little support from statutory services.

Stability appears to have been accomplished in the narrative over past fears of her husband’s suicidal ideation, ‘Although I don’t condone it, I do understand’ (1/22). The importance of this is reflected in some of her photographs she took for the photo-elicitation stage of the research. One shows Dave with a plastic gun to his head, revealing his suicidal thoughts. The follow-up photograph shows her looking disapprovingly over the top of her glasses at Dave with the plastic gun, reflecting how she responds to him when he expresses this ideation. This suggests that just because there is no visual presentation of the ABI it is a significant feature of her life and important to mention, in terms of the hidden aspect of coping with brain injury (Gordon et al, 1988). She discusses this issue of the backstage self versus the front of house self with respect to this, ‘It’s changed him internally but because he puts such a good front on’ (3/460) (Goffman, 1959).

She carries the strain of being the wife of a man with an ABI in terms of the occupational disruption when she expresses, ‘everyday it’s somehow there’ (2/66) (Manskow et al, 2015). Currently she sees herself as experiencing a ‘mid-life crisis’. She mourns the past before her husband had his stroke (that led to the brain injury) and sees an irony in the fact that it occurred on an April Fools’ Day. She still carries some grief for her mother’s death, but this is nothing in comparison to the trauma of her husband’s brain injury and this pervades her thoughts every day (Bruner, 1990). However, there is some cognitive dissonance round her life pre and post her husband’s ABI, in that she finds him easier to live with now, ‘for me, he’s better’ (2/303) (Folkman & Moskowitz, 2000).
There are complexities of being a full time worker, mother to two children and wife of a man with brain injury who needs support, causing role strain (Mauzer & Richer, 1998). Helen identifies strongly with the mother role, having two pre-teen children and discusses helping them with such as their homework and extra-curricular activities, making life busy. Some roles that Helen had to take on in the relationship post-injury are anchored in negative terminology in terms of Dave having to accept them, ‘one blow that and the other blow me having to drive, bless him’ (1/19).

Photographic images presented reflect the family environment and typical family activities, including being proud of her daughter for her achievements. Some new occupational roles have been helpful for Helen to take on, such as family driver, though it has impinged on Dave's identity as the male and the driver in the family, with reluctance from him to give up this identity (Watson, 1996). He still fulfills many of the aspects of the father role, such as prompting the children with their homework and engaging them in family rituals such as baking for special occasions. His fatigue does cause some occupational performance issues though, such as forgetting what time to be places (Headway, 2015). Past habits and routines have become more difficult, such as additional responsibilities of organising family holidays, being the sole family driver and a change in her intimate relationship with her husband, suggesting occupational rupture (Christiansen & Matuska, 2006; Backman, 2000). Expected support from the National Health Service was not forthcoming when needed. The busyness of the worker, wife and mother roles leaves her little time for herself, which she would like, ‘and its hard to actually say, oh I’ll just have a bath and relax’ (3/1546), causing her little time for restorative activities and is an occupational imbalance (Christiansen & Matuska, 2006; Backman, 2000). She does take time for herself when she can, just to enjoy simple pleasures such as walking on the beach, ‘now that I can get time if I wanted to go to xxxxxx beach or sometimes nice just cleaning the bathroom’ (2/673), or taking a relaxing bath when in the house alone, but opportunities for this are few and far between and an occupational imbalance results (Christiansen & Matuska, 2006; Backman, 2000). She would also like to make more time for her friends, just being with Dave, time to develop her Reiki therapy and to be creative, ‘Yes, I had intentions of going arty stuff’ (3/1509). The simpler way of spending time is with vicarious engagement through television, ‘If it just put the telly on, that’s a big mistake cos I’ll get sidetracked’ (3/1548). Helen is able to take pleasure in the small things in
life, ‘It's just the wind in your hair type of thing’ (3/1534), making almost spiritual connections (Baldocchino & Draper, 2001). This is linked to her other activity of Reiki therapy and would like to be a therapist more seriously in the future as it means being able to devote more time to one person in contrast to current day nursing ‘in a way that’s the caring’, (3/1149). Today she anchors some of how she copes as seeking escape from the situation, ‘Er, sometimes, I just wish I could sort of hibernate. Switch off. Disappear.’ (3/1784) (Lowit & Van Teijlingen, 2005). She is appreciative of Dave engaging the children in collective family activities such as baking and creating dolls' houses, ‘He’s a really good dad’, (3/110).

She creates a positive impression of her husband when she describes him as, ‘very intelligent’ (1/12) from the beginning of the interview. Her relationship with Dave is underpinned with statements about the longevity of the relationship, denoting commitment, ‘I've really been going out with him since I was 18 I think’ (1/12). She also creates an impression of a close marital relationship, ‘So that was nice cos I was just with him’ (2/14). However, there is a negative impression suggested pre-injury when she discusses some of his former traits, ‘possibly verging on a bit of a control freak’ (2/48) and when her narrative moves into post-injury she describes him negatively, ‘because he was volatile with the stroke’ (1/19) (Anderson et al, 2009). Their relationship pre-injury could be strained at times due to his temper, ‘but he could be hot headed anyway, so he used to lose his temper now and again’ (1/19). These increased to, ‘massive arguments’ (1/19), post injury to now finding this aspect of Dave's behaviour improved and better than before his injury, ‘In fact I think now he's, for me, he’s better’ (2/303). Overall, the impression she gives of her husband is a combination of positive and negative traits, but changed for the better with the ABI, ‘In fact I think now he’s, for me, he's better’, (2/303), indicating a cognitive dissonance about the ABI experience overall (Folkman & Moskowitz, 2000).

She makes reference to their sexual relationship being affected by his medication, ‘It’s, it's it is difficult because I'm aware of how that affects him’ (2/493), but then rationalises this as something that declines in many couples when they are busy. The nurse identity is anchored in positive terms of being caring and closeness, to be able to understand personal issues in relationships (Tajfel & Turner, 1979).
She expresses agency through involvement with the brain injury charity when she sees herself as having a role in welcoming people, ‘So I’ll just go and say, oh hi’ (3/1034). This theme continues as a sort of quest to make life better for people with disabilities or people supporting people with disabilities (Frank, 1995).

Helen expresses that her emotional relationship with her father was lacking growing up, ‘I always wanted the dad in the movies that was all cuddles’ (2/6) and now that he recognises her living successfully under the circumstances with a husband with an ABI she feels she has some recognition from him at last, ‘so I suppose there’s more kind of mutual respect if you like. He, he was a bit of a distant father’ (3/1687). This gives some sort of resolution to a part of Helen’s life narrative (Bruner, 1990). She is also pleased from a relationship point of view that Dave’s relatives give her similar recognition, indicating value she gains from being seen as altruistic (Babula, 2013).

Helen uses humour to describe an event when her and a health worker went to a conference for people with brain injuries and she was conscious that they may be mistaken for people with brain injuries themselves, ‘they’ll think, they must have really bad brain injuries’ (2/212), objectifying people with brain injuries as not being part of the non-disabled hegemony and an issue for social and personal identity (Goodley, Hughes & Davis, 2012). However, she does see the charity as a rich source of social capital.

In summary, at this point in time Helen’s narrative demonstrates elements of both optimistic, (that her husband is improved in temper than pre-injury) and pessimistic tone (that she would like to escape), alongside stability, (using her nursing approach to understanding) (McAdams, 1993). There are elements of a quest narrative, (wanting to campaign for people with disabilities) and romance, (resolution to lack of emotional contact from her father). This could be summarised by Frank as a chaos narrative and one that is very much still in progress (Frank, 1995).
Appendix S: Analysis of narrative

Participant 9 - Doug – A husband’s story

Positional aspects of Doug’s narrative interview

I had met Doug on a couple of occasions before the first interview, through his charity contacts. This helped me feel very relaxed during the interview, but also he had a very relaxed style and was used to relaying his story as an advocate for people in similar situations.

I became aware part way through the interview that Doug’s wife had acquired her brain injury as a result of neglect in a hospital that had recently been the subject of a national scandal for inadequate care and this immediately conjured up negative images of what their situation could possibly have been like at that time. Although it was quite some years since the incident the enormity of the consequences appeared to hold a deep-seated mistrust of health services and guilt at having misplaced trust in the health personnel at the time of the biographical disruption.

As a therapist with a rehabilitation background I identified with the quest of improving his wife’s functional performance and re-establishing the stable narrative, which is the main focus of his life. It was obvious in the interview that the narrative very much respected his wife’s personhood and rejected the identity of a disabled person, with disappointment expressed when talking about relationships that had been lost as a result. He also rejected a carer identity and saw carers as the paid employees who came in to work with his wife: his role remained resolutely as husband (Lee et al, 2001). I was touched by the generosity of his discussion.

Analysis of Doug’s narrative

Doug is in his seventies and lives with his wife in a small remote rural village. His wife, Rose, had a brain injury, in the form of an embolism, as a result of negligence in hospital, twelve years ago (Francis, 2013). They have been married for over forty years. Both Doug and Rose are white, British and have
lived most of their lives in a large urban environment. They moved to the current rural location to access a good brain injury service to meet Rose’s health and rehabilitation needs. Rose’s needs were not being met where they lived when she had the brain injury in the urban environment. They heard of the much superior service over 250 miles away, close to Rose’s sister and moved as a result of this. At the time Doug had taken early retirement from the civil service and was self-employed in accounting. He was a keen runner. Both of these activities ceased when Rose acquired her brain injury due to Rose being dependent on him, causing occupational disruption (Lund, Mangset, Wyller, & Sveen, 2015). After a legal dispute with the hospital where Rose experienced the neglect, she received a financial compensation package, which pays for twenty-four hour care in their adapted bungalow. Rose has mobility impairments, cognitive issues and seizures as a result of the ABI (Headway, 2015).

Doug’s narrative is over-archingly optimistic (McAdams, 1993), despite him experiencing biographical disruption in mid to late life, which is not been resolved today. He recounts his growing up in positive developmental terms, which may influence this approach to his narrative (McAdams, 1993): his working life began with shop work and led to a management and leadership role, involving significant people management and finance responsibilities. Doug anchors his early working life, as a manager in the Job Centre, as being a difficult place to work, ‘It was one of the worst experiences on God’s earth’ and describes the scene as one of ‘cowboys and Indians.’ (2/54-57), but then discusses his achievement through promotion to management and resolving the difficulties, ‘worked me way up through the grades erm, until er, you know I was running…’ (2/54). There is a background theme and habituation of the importance of health and fitness with pride in personal appearance, which may have sprung from his early career in the men’s retail business and then becoming a keen runner and an athletics coach in his spare time (Kielhofner, 2008).

The optimistic tone is reinforced by his enduring close relationship with Rose, whom he describes as always being his best friend as well as his wife (McAdams, 1993). He introduces a certain mystique and coincidence to their first meeting, ‘we actually came back from London on the same day’ (2/28), suggesting a romantic plot (Frye, 1957). They have always enjoyed spending
leisure time in each other’s company and were actively involved in taking part in and developing the local running club. He holds happy memories of himself and Rose, holidaying at home and abroad with friends. There is a background pessimistic tone of the struggle, with the stress and physical strain of his wife requiring physical and cognitive support (McAdams, 1993). The financial compensation from the negligent healthcare doesn’t make up for his daily anxiety and stress, though it allows a team of paid care staff to support his wife (Martin, 2012). He uses the financial compensation to implement a well-thought out package for Rose and his optimistic tone is reflected in his careful commentary about his wife being in a recovery phase and undergoing rehabilitation rather than being cared for (Berger & Luckmann, 1986).

Overall, Doug’s is a progressive narrative, mid-way through the process of overcoming adversity and yet to be resolved, though he holds an optimism that resolution will come (Gergen & Gergen 1986). Doug’s life story takes an extreme regressive turn when he describes his wife becoming ill and her lack of hospital care. He has yet to achieve the position of the stable narrative him and Rose experienced pre-injury (Gergen & Gergen, 1986). Rose’s ABI is anchored in catastrophic terms, when he talks about the night he left her in the care of hospital staff when she was neglected, ‘the worst decision I’ve ever made’, (1/78) (Berger & Luckmann, 1966), to express the long-standing impact of her situation since making that decision. He still carries guilt from putting his faith in the hospital staff at this time and the resulting negligence that led to their biographical disruption. He looks back at this time as one where healthcare personnel were under resourced rather than uncaring, but nevertheless basic care was not forthcoming and catastrophic mistakes made (Francis, 2013), ‘the care at the hospital was absolutely abominable’ (1/108). He carries skepticism of some healthcare to this day, in a protective way for Rose, almost as if he still prefers to have overall charge in case a second catastrophic mistake is made.

His narrative takes on agency when he makes the decision to move out of the geographical where they have lived most of their lives: they were struggling to cope with Rose’s daily occupational performance at home and no rehabilitation, or progression was being made there. They made contact with a health worker, through Rose’s sister over 250 miles away and he described a dedicated and robust health and social care service for people with ABI (Berger & Luckmann, 1966). This triggered an immediate move to this new area. It is defining moment
in the narrative. The support services put in place resulted in a significant increase in occupational performance for both Doug and Rose, in at last they were able to establish coping strategies (Verhaeghe, Defloor & Grypdonck, 2005).

Since living in the new area Doug’s narrative is overall one of progression, with a number of regressive episodes when Rose has further episodes of cerebral infarction (Gergen & Gergen, 1986). The discourse around the much better head injury service in the rural area is preceded by words that heighten the difference between that service and the one in the area they left behind, ‘I mean that was fantastic’ (2/457). He continues to strive for her progress through rehabilitation to this day, even though their circumstances take a considerable toll on his own health, ‘The fact that erm, I’m sort of you know under constant stress here’ (3/2). (Anderson et al, 2009). He talks about just maintaining a status quo not being what they want: they want to see progress through rehabilitation. Disillusionment is voiced over the national variety in essential support services for people with ABI and their families. The sacrifice of losing their social circle is a disappointment, ‘never get an invite to any, to anywhere’, (3/1299), but is compensated for by the far superior quality of life accessed in this rural area due to better healthcare services and supportive local acquaintances. He has strong beliefs about people with ABI having access to support to enable them to make progress and develop (Ben-Yishay, 2008). He became involved with a brain injury charity to encourage this. Not only has he become involved but utilises his managerial and finance skills to act as a leader in providing support for people through the charity, which demonstrates a form of occupational persistence or habituation (Kielhofner, 2008).

In managing Rose’s rehabilitation package, in partnership with Rose’s niece, he also displays agency, actually to the extent that he finds it difficult to withdraw and hand the responsibility over to others. This may be partly driven by guilt in that he placed his trust in the nursing staff the night Rose acquired her brain injury, when he went home from the hospital (Verhaeghe, Defloor & Grypdonck, 2005). His interpersonal relationships with the rehabilitation team are very much as a human resource manager who oversees the budget. Doug’s discourse reflects habituation in that it has the thread of his management and finance background running through it, for example when he discusses managing Rose’s care, ‘So, we’ve really been operating a, a rehabilitation policy of our
own’ (1/323) and, ‘her niece has developed a erm, a healthy eating er, strategy’ (3/341) (Kielhofner, 2008). Fun and love is introduced into his wife’s rehabilitation package, whilst striving for improvement in her functional status e.g. increasing her standing tolerance by way of her kissing.

The duality of being the manager of Rose’s rehabilitation package and her husband causes role conflict for him (Mauzer & Richer, 1998). He feels that he is constantly ‘on duty’ in that if he tries to relax and be Rose’s husband, the employed staff constantly turn to him for resource management in his manager role. He knows that he needs to withdraw at times and find outside interests to relax and decrease the strain experienced by managing Rose’s rehabilitation but he lacks the social contact opportunities due to the rural environment being a commuter area for the nearest city. He also feels guilt at taking time away from his wife as they have always undertaken leisure activities together (Verhaeghe Defloor & Grypdonck, 2005). Her ABI cognitive deficits mean that it is difficult to explain these needs to Rose and she becomes anxious when he isn’t around, which causes further health complications by way of triggering her seizures, ‘and her you know, it’s almost obsession for me being there with her’, (3/192).

Within the narrative of progression there is still the essence of a broken narrative where adversity has yet to be overcome (Gergen & Gergen, 1986). He sees biographical disruption as discriminating: friends and family continue to be involved in their lives but to a lesser extent. The change in health and social status brings out rejection from some and positive caring qualities in others (Tajfel & Turner, 1979). Environmental barriers are posed in accessing the houses of friends and family due to Rose’s use of a wheelchair. He views the reduction in invitations as being due to inconvenience as opposed to having the social identity of being in a relationship with a disabled person (Goffman, 1963). Doug explains that less contact with close relatives is due to environmental barriers preventing them from accessing the relative’s house, rather than it being to an aversion of disability or ill health but alternatively it could relate to the social identity of marginal people (Tajfel & Turner, 1979). Also, friends that they lost when Rose became ill, he explained, found it too upsetting. He continues to explain his lack of health locus of control by his words, ‘the potential for disaster is still there’, (2/785), linked to his mistrust of hospital staff and Rose not being able to manage her own healthcare.
He attributes his wife’s fitness and resilience to her current sturdy health status and the improvements she continues to make, ‘She’s, she’s a bloody miracle. Call her our Angel of the North’, (2/825). He and Rose do not appear to hold personal identities connected with disability, as Rose makes it clear that she prefers not to holiday with disabled people (Tajfel & Turner, 1979). Doug’s story is full of romance for Rose and their long-lasting marital relationship and hopes for Rose’s continued improvement (Frye, 1957). Doug’s story is anchored in romance and caring at a number of junctures, for example when he describes the renewing of the wedding vows ‘on board the ship’, which he introduces as being, ‘a surprise’. He talks about how they would hold hands, even though married for some time, (1/20), inferring that their marriage was always special. He also expresses his dismay at no longer having, ‘private time’, (3/389) or intimacy in the relationship. Doug very much has the identity of being a romantic partner in a relationship with his wife. He also talks about holding hands with Rose and this being ‘just one of those things that we do’. However, he can no longer have the husband role as he did before, ‘I don’t really have a husband role’ (3/383), in that he has little privacy with Rose and even sleeping arrangements are interrupted, disturbing intimacy in the marriage (due to Rose’s care needs during the night).

Doug’s identity comes across in his discourse in a number of forms (Berger & Luckmann, 1966; Tajfel & Turner, 1979) besides the romantic husband. He holds the identity of being a manager, (with accompanying status) and of being an individual who takes pride in his appearance (and his wife’s). An example of the imagery used in taking pride in Rose’s appearance is when Doug discusses her enjoyment of getting her nails painted, ‘getting her all tarted up to go away’, (3/1402). He maintains her femininity through this discourse (Willig, 1999). The gender aspect of his life is discussed when he discusses the need for male-orientated activities. Doug discusses the role strain he is under in that he is the manager of Rose’s rehabilitation package (along with his niece), and the staff turn to him for advice, yet he still has a need to escape the stress of this environment (Lowit & Van Teijlingen, 2005). It is an all-female environment and he has a strong need to identify with male company. He objectifies this when he creates an impression of how having so much female company can be overpowering by declaring, ‘I would say I’ve got fourteen mother-in-laws!’ (3/757) (Berger & Luckmann, 1966).
He uses imagery about striving for improvement by saying, ‘you’ve gotta be actively encouraging and pushing the people to develop’ (2/530), and encouraging people to move to the zone of proximal development and reach their potential (Vygotsky, 1978). His agency is expressed in management speak as ‘definitely our policy’ (2/534) (McAdams, 1993), in that he has a strategy for action. He talks about opportunities for people with ABI and ‘with the right help, er they can do lots to improve themselves’ (3/604). He also discusses this striving for improvement with Rose, in that ‘We don’t do caring for Rose. We do rehabilitation for Rose’ (3/1025-1027) (Lee et al, 2001). This creates an impression that with time and guidance Rose can recover and reach her potential again, which underlies Doug’s romantic narrative of having met adversity and coming through to a positive end point (Frye, 1957).

Doug is careful in the words he chooses to explain the psychological effect of coping with a wife with an ABI, by saying, ‘I had to have erm, er, psychological input on a couple of occasions’ (3/431) (Berger & Luckmann, 1966; Willig, 1999), as opposed to discussing mental ill health. This may be a way of avoiding a stigmatising label (Goffman, 1963) or him not holding a personal identity of someone who has periods of mental illness (Tajfel & Turner, 1979) and using splitting as a means of cognition (Cashdan, 1999). Another potential example of splitting is through their choice of holiday location, when it is depicted in terms of seeking out normalising locations and avoiding the hotel that, ‘I mean it really just caters for people with disabilities’ (3/797). Doug uses a degree of objectification to dissociate his wife from the disabled community, ‘she doesn’t see herself as being part of that community’, (3/799) (Berger & Luckmann, 1966).

Doug's occupational identity comes across as being productive, well-presented and having leadership and managerial skills, from his early work in men's retail, through to his work as a civil servant, managing budgets and people, developing the athletics club, through to managing Rose’s rehabilitation package and taking a leadership role in the head injury charity. He demonstrates this as an occupational persistence or habituation throughout the narrative (Kielhofner, 2008). The fitness interest is reflected in healthy eating and the pride in appearance continues through activities such as her having her nails painted. He looks to the future in terms of hoping to re-establish past activities such as holidaying abroad when his wife improves in her occupational performance. His
leadership and financial skills have been put to good effect in his charity involvement where he has been an instigator in providing development activities for other people with ABI. Doug has played a significant leadership and management role in the brain injury charity in terms of organising events and campaigning for the development of services for all people with ABI. He talks of a quest to develop the occupational performance of others through such routes, recognising potential in people, if they are given the appropriate resources (Ben-Yishay, 2008). This links with his optimistic narrative tone and his display of agency (McAdams, 1993), by his making things happen for others and not just Rose, resulting in developing social capital through the charity (Bourdieu, 1986).

This charity involvement can be interpreted as a display of altruism and also in creating something that exceeds oneself (Frankl, 2004; Babula, 2013), as he continually tries to hand over responsibility to others allow him to withdraw due to his declining health.

He does hold part-ownership in a racehorse with some friends locally. This allows him to engage in a male-orientated activity with friends in the pub and also Rose enjoys the contact with the animals when they visit the stables together. He talks in a romantic way about the connection Rose has with the horse and her being able to influence it. He enjoys the identity as a racehorse owner when they are able to see it run, again, reflecting his personal identity as a smart person with status (Tajfel & Turner, 1979). Further opportunities to seek out more male company, are reduced, due to the rural area where they live being a commuter village and many local men being out at work all day.

Restorative activities in the form of foreign holidays are discussed frequently, including cruising, which he and Rose would like to return to when she is well enough and her rehabilitation package comes to fruition. Occupational disruption does reoccur due to a lack of health locus of control (Sanders & Suls, 1982): Rose has periods of seizures that disrupt routine and make her physically unwell. She has also had further cerebral infarction since the first ABI. Lack of suitably adapted external environments means that activities are limited to places where they can access toileting facilities or are not too far away from home (Leonard Cheshire Organisation, 2010).
It is important to Doug to see the activities that he and Rose engage in as ‘normal’ rather than centred around disability, ‘we try to erm, make life as normal as possible. We try and do the normal things’ (2/441443), and declares that this is the only way that they can cope (Verhaeghe, Defloor & Grypdonck). This may be the importance of holding on to their ‘normal’ identity due to use of splitting (normal versus disabled) as a means of cognition (Cashdan, 1999). They engage in activities such as pub meals and shopping, as well as the holidaying, in this respect.

Doug's routine is upset by sleep disturbance. Rose isn't cognitively able to understand that his sleep being disturbed makes it difficult for him to continue to cope and so the sleeping arrangement of them sleeping together remains, even though it disrupts Doug’s sleep. His caring nature is for him not to cause her any distress so he doesn’t address this with her, plus he sees her improving in the future and perhaps being no need to make changes at some point. The result is an occupational imbalance for Doug (Martin, 2012) in that he can feel tired and anxious.

Overall, Doug’s narrative is of a husband and definitely not a carer. It follows a romantic theme by way of describing a stable life, adversity and then hope of overcoming adversity (Frye, 1957). However, at the present time the narrative has yet to reach the final stage of overcoming the adversity and is part-way through.
Appendix S: Analysis of narrative

Participant 10 - Elizabeth – A wife’s story

Positional aspects of Elizabeth’s narrative interview

Elizabeth appeared to me to be a keen participant in the research. She came across initially as placid and someone who is normally non-confrontational and almost timid. She and her husband had prepared a room in their house that would be undisturbed and private, in an almost professional manner. This was a room converted from a garage that had walls covered in family momentos and family photographs. Elizabeth explained that she used to use these to make up stories for her children when they were small.

She seemed to view life as ‘moving forward’ and expressed decision-making in order to facilitate that. She certainly appeared to have no polarization in terms of disability / non-disability, instead respecting personhood. She struck me as ‘matter of fact’ and not dwelling on the negative aspects of life and being grateful for the good life she finds herself in. This seemed to limit the expression in the first interview and led me to have to resist the urge to deviate from the CQUIN approach.

Overall, I could sum up her approach to life being that everything works out in the end, similar to my own approach.

Analysis of Elizabeth’s narrative

Elizabeth has been married to Trevor for almost twenty years and they are in their fifties. They live with their teenage son and daughter in the countryside and her mother lives in an annexe part of the house. They are about five miles from the nearest town, which is small and very rural. She is white, British and local to the region. Trevor acquired a brain injury as a teenager from a climbing accident. The resulting symptoms of his brain injury are not immediately obvious but he does have some facial disfigurement. Through listening to Elizabeth’s story Trevor’s symptoms can be described as night-time epilepsy, memory problems, fatigue, facial nerve damage and he has had low mood in the past.
Elizabeth has only ever known Trevor since acquiring his brain injury and has always objectified the injury symptoms as being separate from the person that he is (Berger & Luckmann, 1966).

She has begun her own business a number of times in the past and is in the early stages of developing a network marketing business with Trevor. She finds this work exciting and it seems to suit Trevor's occupational needs as he can pace himself to avoid fatigue and involves working with people, which he is good at (Headway, BSRM&RCP, 2003; Headway, 2016b). Elizabeth also works part-time as a classroom assistant with children with special needs. Initially she was employed in the school as a nursery nurse and then she was asked to move through the school with particular children whom she had got to know in the nursery. She is no longer happy with this arrangement and would like to work with the network marketing venture fulltime. She would like to add other entrepreneurial ideas to the business, such as linking it to running a café with a bakery attached, which would be run with other members of the family. She displays an occupational persistence or habituation in entrepreneurial work (Kielhofner, 2008).

Elizabeth's tone is clearly optimistic (McAdams, 1993), seeing past any potential problems with respect to Trevor's ABI symptoms (BSRM&RCP, 2003; Headway, 2016b). Her focus is on her family and the family cohesiveness. Elizabeth's narrative begins in a supportive family environment and is initially progressive (Gergen & Gergen, 1986). She talks lovingly of her parents and her early family life, which could be an influence on her optimism (McAdams, 1993). Whilst living in this supportive family environment she had some negative experiences that she still describes today as ‘etched in my mind’ (1/45). When she reached school age she was singled out by teachers and humiliated in class for being weak at mathematics. This had a great influence on her personally and was an epiphany moment (Bruner, 1990) to make the decision to become a nursery nurse, to try and help children who needed extra time and prevent them from experiencing similar humiliation. She turned the negative experience into a positive and thus displayed agency, at this potentially regressive point in her narrative (Gergen & Gergen, 1986). This may also explain why she strives to have her family around her today, in terms of a protective barrier from this childhood experience.
Being at school in her teenage years was more stable in her narrative and she describes having normal friendships and enjoying these times and completing her nursery nursing qualification in college. However on leaving there were few vocational opportunities in her chosen pathway and so she decided to open her own nursery. Her family network continued to be supportive by way of her parents giving her finance to help purchase premises to run her own nursery business. This was the beginning of an occupational pattern of working to help others and engaging her entrepreneurial skills (Kielhofner, 2008). The family support element is something that Elizabeth has brought forward in her narrative today, thinking of ideas to start businesses for her own teenage children and husband, as well as helping elderly relatives. This is also an expression of agency that illustrates the progressive narrative, by way of making the decision to start her own business (Gergen & Gergen, 1986; McAdams, 1993).

She appears to take pride in her recollection of the activity of running the nursery, by way of gaining some recognition for respectability, in that the social services department always asked her to keep places open for children who needed nursery care urgently (Csikszentmihalyi, 1990). She ran the business successfully for a number of years before the economic climate changed. The closure of the business is described positively by way of the premises sale allowing her to purchase a house in a smart rural town, where she took a job in a state nursery, thus the progressive narrative continues (Gergen & Gergen, 1986). She describes this time with agency, ‘I had to make the decision’, (1/162).

It was during this period that Elizabeth met Trevor. She recounts her role as daughter and assisting her mother when her father was ill, including taking him to a special swimming class where Trevor helped out. Trevor had acquired a brain injury some years earlier and was an actor, who, by nature of his profession, had irregular work. Elizabeth expresses romance in her narrative when she describes the short courtship, ‘So I hadn’t known him that long but we just knew’ (1/266). The romantic expression is another aspect of a progressive narrative (Frye, 1957; Gergen & Gergen, 1986). She saw past any potential problems with respect to Trevor’s ABI symptoms ‘It was part of life and I knew a lot of caring cos with Dad having Parkinsons’ (1/284). Elizabeth objectifies Trevor as ‘a person’ i.e. stressing his personhood, as opposed to his status as someone with an ABI and impairments, ‘He was concerned about his face. His
paralysis but that didn’t bother me at all. It was him as a person’, (1/5), (Berger & Luckmann, 1966). She also objectifies a ‘normal’ marriage relationship by the manner in which she discusses that she knew the full extent of his symptoms before entering into it, ‘I knew he had all his problems, but he was on his medication and, and it was, seemed alright as long as I reminded him to take them’ (1/270-272). This is a stance that she holds to this day.

She became a wife and continued working in the school. On becoming a mother Trevor became the house-husband, with acting work drying up, compounded by issues of fatigue and memory (BSRM&RCP, 2003; Headway, 2016b). Elizabeth utilises imagery that indicates a progressive narrative by way of describing their houses ‘Moving to bigger and bigger’ (1/5). Elizabeth continues with a generally progressive or stable narrative, with episodes of regression that she does not dwell on e.g. her father dying of Parkinsons’, animosity from a neighbour when living in the rural town and Trevor’s symptoms impacting on the family life (Gergen & Gergen, 1986). This brief mention made to periods of low mood in Trevor’s life and how this may have impacted on him and family relationships may be a form of impression management in the narrative (Goffman, 1953) or Elizabeth’s coping mechanism of not dwelling on negative issues, which forms the progressive narrative (Gergen & Gergen, 1986).

When her second child was born Elizabeth decided that she wanted to spend more time with her children and took half-time employment for additional family time. Her focus was on the mothering role and the family cohesiveness (Hogg & Vaughan, 2014). After some years they wished to move into a large house with her mother and begin a bed and breakfast business, another illustration of the habituation of entrepreneurship (Kielhofner, 2008). However they did not have their offer accepted on the potential premises. She puts this down to fate as the purchasers went on to have many issues with the house (Strom, 2014). Instead they moved in with Elizabeth’s mother, in her large house in a very rural location. There is an element of objectifying the family as a large, idealistic and supportive phenomena by way of her future dream of the whole family being together in one large house, ‘I’d want a big house and everybody together’, (1/619) (Berger & Luckmann, 1966). She discusses the age of her mother and Trevor’s parents and suggests that they may have a role in the near future of taking more responsibility for them, due to aging, ‘Cos they’re in their nineties and Mum’s very late eighties’ (3/848). She talks of wanting to have the whole
family together around her and help them in terms of parents not going into a home and finding business interests for her children, ‘Nobody else is going in a home. At all’ (1/611)

Elizabeth would like to terminate her work in the school now that it has become increasingly stressful and she doesn’t enjoy it anymore, as perhaps in being a believer that work should make us happy (Morris, 1888). The way she describes her current role in a school that she is dissatisfied with illustrates being able to have little power in her current work role, ‘And then they, the Head likes to mix things up’ (1/220). The desired agency is very apparent when she discusses being her own boss, ‘But if you want to succeed, then you’ve got to do it yourself’ (3/58), (McAdams, 1993).

However, her narrative comes across as power-sharing in the relationship with Trevor. Elizabeth anchors the role of mother to having to be the one who takes care of most of the household duties, ‘Yeah, and also sometimes I suppose as a woman, you end up doing all these things for the family’ (3/109) (Hogg & Vaughan, 2014) and adopting typical gender family roles. She and Trevor do share the cooking. She does the majority of the cleaning and tidying and there are some issues about handing this task over to Trevor and often he can’t remember where he has put something that she needs later, due to his memory problems (BSRM&RCP, 2003; Headway, 2016b).

Elizabeth comes across as being open and honest without significantly trying to manage an impression of self or Trevor (Goffman, 1953). Her dialogue emphasises the partnership aspect of the relationship, in terms of being supportive in a relationship that is equal. For example, when she explains how they discuss things after they have a disturbed night due to his seizures and forgetting to take medication, ‘Cos he knows if he has a bad night, he’ll look “Oh I forgot to take them” “Yeah. I forgot to remind you.”’ (1/311-313). She gives a positive impression of Trevor throughout the narrative, with an example being when she talks about him wearing breathing apparatus at night, ‘I don’t envy him having to wear it, but he does very well’ (1/374-376), (Tajfel & Turner, 1979). Though perhaps impression management is significant in her image of the equality in the marriage by way of denouncing her role as Trevor’s carer and the power shift in any relationship where one partner is the carer for another (Lee et al, 2001). She makes it clear that although she is a caring person i.e. accepting
of a partner with some issues, she does not identify with the role of carer for him, ‘Partner. I’m not a carer yet, I mean one day it might come. He might be mine. I don’t know, but I don’t, I feel we’re a partnership for it’ (1/1952-1956), (Lee et al, 2001).

In the past Elizabeth has enjoyed creative activities that engage her with ‘flow’ (Csikszentmihalyi, 1990) but at the moment she doesn’t have time for these, with household duties, part-time work and starting a new business venture. These included knitting with a machine and card making which encourage flow and relaxation, as well as being potentially expressive in the card making (Csikszentmihalyi, 1990). In the past these activities allowed Elizabeth agency in terms of making them for another business venture at the time, which was selling magnetic bracelets, cards and knitted items at country shows. Not being able to engage with them currently due to other duties suggests a lack of occupational balance (Christiansen & Matuska, 2006).

In terms of leisure pursuits currently she has a love of nature and the rural environment where she lives allows her vicarious participation in this from the windows of the home. This could be seen as a restorative activity of low psychic demand (Csikszentmihalyi, 1990). She engages in community activities such as the Women’s Institute and visiting National Trust properties. She describes herself in a joking manner as ‘a pillar of society’ (3/1360) by being a member of the Women’s Institute, suggesting that she has gained status and respectability by becoming a member, as an example of anchoring in her speech (Berger & Luckmann, 1966). Membership was something she inadvertently gained by accompanying her mother to allow her mother to have social contact, thus continuing her helper role (Hogg & Vaughan, 2014). However it also gives her the opportunity for business contacts. Trevor and her like to holiday in their caravan, either with their son and daughter who are in their late teens or without, but they rarely get the opportunity to engage with this now due to new entrepreneurial venture (another example of habituation) (Kielhofner, 2008).

Recently her and Trevor have begun a network marketing business, which is developing and she is hoping it offers potential, thus the progressive narrative continues (Gergen & Gergen 1986). She enjoys sharing the work with Trevor and working with him. They have developed a system of recording and colour coding, by way of organisational aspects of the business and this makes it
easier for Trevor to engage with the business effectively with his cognitive issues (BSRM&RCP, 2003; Headway, 2016b). Self-employed and being able to specifically tailor the work to Trevor’s abilities and needs (such as taking extra time and fatigue), overcomes some of the employment issues Trevor has had negative experiences of in the past. Elizabeth can help in a supportive way when Trevor requires assistance. This continues to gives Elizabeth the agency, which she has enjoyed as being her own boss in the past (McAdams, 1993). This is an example of occupational adaptation (Nelson, 1988). It also fits with the overall projected narrative for the future of the family working and living together. The entrepreneurship can be seen in terms of recognising her occupational potential and being agentic in terms of trying to achieve this.

Involvement of the family could be seen in terms of gaining value from something that exceeds you and may bring some harmony and resolution to her two teenage children being able to establish careers and future success (Frankl, 2004). She would like to extend working with her family as they grow older and she is thinking about setting up a café and bakery as her daughter is a keen baker. She has the vision of the business ideas being run alongside each other by her family members. ‘Cos (daughter) would like a bakery, so we’re trying to think, “Right, well that’ll work round that”’ (1/872-874). She is finding the new business exciting due it being a new venture with future development potential, all evidence of a progressive narrative (Gergen & Gergen, 1986). It may also link to the progressive narrative in terms of a ‘happy ever after’ scenario and image of contentment surrounded by loving family (Frye, 1957).

Elizabeth’s way of coping is pragmatic and she takes the attitude that everything will work out in the end. She feels lucky with the life that she has, stating that she is ‘quite happy with my little lot’ (1/1946). She doesn’t know what the future will hold for her and is very accepting of this. She describes her life as being good so far and that she is happy and in a solid relationship with her husband. The carer role in being a wife of a man with an ABI is firmly rejected, ‘He has his moments. But we all do’ (3/1500-1502) and sees the only barrier to their lives to be the times when Trevor is not able to drive to access places when she is at work, as there is a continual threat to loosing his licence posed by the ABI symptoms (Lee et al, 2001).
Appendix S: Analysis of narrative

Participant 11 – Diana – A mother and carer’s Story

Positional aspects of Diana’s narrative interview

Diana was very welcoming and homely and keen to tell her story about life as a mother of an adult son with ABI. Her son was there to welcome me and then left politely as he knew the research was with his mother, even though he was the protagonist in Diana’s story. Diana welcomed me as a researcher from a university and reference or acknowledgement to my being an occupational therapist was absent. She came across as a pragmatic mother, with obvious humour and irony in her story, who dwelt on the positive aspects of her life and minimalised the negative aspect. (This was in contrast to her daughter, who arrived at the end of one interview, whose story was more of anger and frustration with the same protagonist.)

Diana was an easy interviewee to warm to, displaying a motherly, protective approach to her son’s situation. She was articulate and admitted to ‘putting the bad things out of my mind’ at the close of one meeting. She was a similar cultural background to myself and of similar age to my own mother, with similar interests and occupations.

Analysis of Diana’s narrative

Diana is widowed, in her seventies and lives alone in a UK rural village approximately fifteen miles from any nearby town. She is white, British and local to the region. Her son, Gordon, is in his thirties and experienced an acquired brain injury sixteen years ago, when his car collided with a farm vehicle on a country road. He lives in rented accommodation in the same village. The resulting symptoms of his brain injury are not immediately obvious as none are visible. Through listening to Diana’s story it can be presumed that Gordon’s symptoms can be summarised as fatigue, visual impairment, rigidity and obsessionality and impairment of executive functioning and social skills (in some situations) (BSRM&RCP, 2003; Headway, 2016b). Gordon is the youngest of Diana’s four children and she has been a housewife since her first child, over
fifty years ago. Her family is supportive and visits her regularly. Diana appears to be the matriarch of the family of two adult sons and two adult daughters, yet turns to the older daughter to intervene in a business-like way if they come up against barriers from statutory services.

Diana’s story is of an overall objective or stable narrative tone (McAdams, 1993) as opposed to optimistic or pessimistic. She declares that she is happy living alone, with her family nearby, ‘I am a housewife and I have a family of four. And I’m perfectly happy living on my own’ (3a/5). Diana begins her narrative with declarations about her primary role in life as a housewife and mother (Tajfel & Turner, 1979; Hogg & Vaughan, 2014) and how her family is the most important aspect of her life.

Her formative years are not revealed and she begins her story at the point that her children are born and how she has nurtured her family as they have grown up. She talks about her two sons and two daughters being born to two different husbands, both who had premature deaths, leaving her to fulfill this important maternal role. She does not dwell on these aspects of a regressive aspect of the narrative (Gergen & Gergen, 1986), which could be utilising the coping mechanism of avoidance for aspects of her story that have been difficult to cope with (Lowit & Van Teijlingen, 2005). She describes a stable narrative in terms of nurturing the children. She intimates that Gordon had a special connection with her as the youngest child growing up, who never knew his father, ‘Mammy’s blue-eyed boy’ (1a/6) and creates an impression in the story that he is of good nature, loving, ‘He was always a very, very loving son’ (1a/6) and had a normal development, ‘Did all the things that lads do’ (1a/6) (Erikson, 1959). This may be in order to position Gordon in a place as a ‘good person’ who is the victim of a tragic accident, part of which was contributed by his employer at the time persuading him to take on more responsibility that his age warranted, ‘They hounded him.’ (1a/8). (Harre, 2009).

Diana’s narrative becomes regressive when she talks about the day of Gordon’s accident. This occurred two days after moving house on a Friday and she uses a superstition of it being bad luck to move house on a Friday as a regret in her actions (Strom, 2014). Despite making reference to superstition she no longer holds religious beliefs, as she cannot imagine if there were a god that he would allow her son to suffer like he has. She draws on language to signify adversity,
'knock at the door' at the time of hearing about Gordon’s accident, even though the news came via a telephone call (Berger & Luckmann, 1966; Willig, 1999). Her way of coping with this biographical disruption to her role as a nurturing and caring mother was to run away from the hospital initially, a form of denial (Lowit & Van Teijlingen, 2005). This could have been because her expected romantic narrative for her four children was one of a happy and successful life, to ‘get the best for them in their lives’ (Frye, 1957). She expresses sadness for the lost hopes and dreams she held for her son and his lost occupational potential (Kuo, 2011), ‘But it’s awful, it’s awful when you see a young lad that had all his future ahead of him.’ (2a/91). The coping mechanism of denial continues to an extent when she declares, ‘You remember but you don’t want to go over it all again’.

She expresses disappointment at the hospital care he received in terms of attention to his feeding needs and the cleanliness of facilities. There is a ‘taken for granted’ expectation that health services will be caring, which was not met for Gordon in Diana’s narrative. It is not uncommon to experience this type of conflict in medical encounters (Francis, 2013).

Some progression in the story takes place as Gordon overcomes medical uncertainty but she becomes very disillusioned that good quality rehabilitation care is not available on his hospital discharge, ‘Once you’re out of hospital Claire, that’s it!’ (1a/121) expressing disappointment that long term needs are not met (Kneafsey & Gawthrope, 2004). The disappointment in the narrative continues when she gives examples of not being able to access appropriate services. Gordon had an acute period of rigidity and obsessionality (BSRM & RCP, 2003; Headway, 2016b) where he hoarded. Diana would have liked health and social care services to have employed a firmer approach in dealing with this negative behaviour and only found this in one worker, ‘but the rest obeyed all the little rules and wouldn’t (sweep away the rules) cos they didn’t know him’ (1a/121). This could be interpreted that the care services took a client-centred approach, with Gordon expressing wanting to continue to hoard, as opposed to specifically identifying his hoarding behaviour as a symptom of obsessionality from the ABI and then treating it with a more suitable approach such as behavioural techniques or medication (Thorndike, 1911). The hoarding behaviour had serious consequences as it led to him being evicted from his first flat.
Diana expresses more regression in her narrative following Gordon’s accident when she describes the reaction to the car crash from police services. Diana positions Gordon positively in her story as not hurting anyone in the car crash, ‘he didn’t hurt a soul’ (2a/119) and was upset at a suggestion by the police that they may prosecute (Gergen & Gergen, 1986). She expresses irony, ‘if only’ (2a/127) and describes Gordon’s life as a consequence of the crash as, ‘Erm, but, but to my mind what he’s got now’s a life sentence’ (2a/145). However, she minimises this description of his life when she refers to the present day, ‘But er, but never mind he’s a lot better now than he was. He’s marvelous’ (2a/147). This is one example of Diana expressing cognitive dissonance (Festinger, 1957).

An epiphany moment is reached in the narrative a few years post-accident (Bruner, 1990), when the family learns through a television documentary, of a boxer with an ABI who had depression. They thought that psychiatric intervention may help Gordon, but experienced resistance in being able to move to Gordon accessing mental health services as his healthcare sat within head injury services, ‘We couldn’t get to a psychiatrist. Erm, I don’t know, they kept putting every obstacle in our way’ (1a/137-139). Diana employs agency in her narrative (McAdams, 1993) when she asks her older daughter to intervene at this point, who she describes as ‘a business woman’. The resulting pharmacological intervention improved Gordon’s mood (which had involved suicidal thoughts) and decreased the hoarding behaviour (Headway, 2016b).

Diana has been very protective of Gordon over the years, since his ABI. She moved from denial as a coping mechanism to engaging in her caring, nurturing mother role. She describes herself as feeling like a tigress, protecting her young. This indicates an habituation in her mothering role (Kielhofner, 2008). One way is in being protective by ensuring that he isn’t exploited by inappropriate vocational rehabilitation placements. She sees businesses that take people with ABI on vocational placements as exploitative and not understanding of their needs, such as being able to cope with fatigue (BSRM&RCP, 2003; Headway, 2016b). She understands that Gordon may no longer wish to take seasonal work that he has been offered, as it becomes difficult for him to re-access housing benefit payments when the work ceases, thus not encouraging people with disabilities to work.
A second area of Gordon’s life which Diana protects is his objectification by her next door neighbour, ‘He’s a right horror’; he sees Gordon as being active yet unemployed and labels him as being a ‘benefits cheat’ (Moscovici, 2000). This may partly be due to Gordon having few outward physical signs of ABI and thus exhibiting a predominantly hidden disability (Olney & Kim, 2001). Her neighbour is taking a viewpoint about a work ethic being of high value in life (de Botton, 2009), yet he fails to understand that Gordon no longer has the performance capacity to hold down regular employment due to his ABI. Or it may be that he does understand that Gordon has a disability yet values usefulness over dignity (Frankl, 2004). Diana employs agency in her story with respect to this: when the neighbour threatens to report Gordon to authorities Diana has approached her solicitor and the police herself to see if they can stop this objectification and animosity (McAdams, 1993).

It is suggested that Diana may prefer not to dwell on the negative elements of her experience with caring for Gordon by way of impression management of Gordon’s identity, again habitually feeling protective as a mother (Kielhofner, 2008). This became apparent when comparing the content of Diana’s narrative with a brief interaction with Gordon’s sister: his sister was angry and explosive about Gordon’s present life situation and suggested that Diana’s version of events was different to that of other family members. An explanation of this can be drawn from narrative theory, about an individual’s version of the same event varying from another’s version, with her daughter’s narrative being still one very much in progress (Polkinghorne, 1988). It may be that Diana’s daughter experiences malaise from the stalled plot of her brother’s life (Frank, 1995), and copes in a very different way to her mother, who prefers not to dwell on this.

Diana has expectations about the norms of social behaviour and treating people respectfully. She expects her son to follow social norms and is disappointed when he doesn’t as this highlights his difference from other people (Conneeley, 2002). She tries to manage Gordon’s social identity by trying to modify his behaviour in social situations such as parties, when he likes to be the centre of attention. She finds it upsetting when he embarrasses himself and declared in a private manner, ‘my daughter would hit the roof if she heard me’ as she described these social situations as pointing out to people that he is ‘not quite right’ (2b/508). This is an example of cognitive dissonance in so far as at other
points in the narrative she describes Gordon as marvelous and declares his normality, 'But I mean he is perfectly normal' (3c/14)(Festinger, 1957). This is also an example of multiplicity in her construction of Gordon (Berger & Luckmann, 1966).

Diana is anxious about Gordon in terms of his health locus of control and the lack of control she has over his behaviour (Sanders & Suls, 1982). She worries about her son’s welfare on a daily basis, especially as he has talked about suicide in the past, 'It’s a constant worry the whole time' (2a/73). She continues with the mothering and protection, even though Gordon is an adult, ‘You can go where you please so long as I know where you are’ (2a/65). Diana takes responsibility for many of his day-to-day tasks such as cooking and cleaning, even though he lives independently. This dependence causes her anxiety about the future as she realises there is no one to undertake this role when she dies. She describes herself as ‘his centre point’ (3a/405). ‘That’s what worries me when I think of when my day is done, what’s gonna happen to him?’ (3a/403). It is common for elderly carers to live with the anxiety about who will care for their son or daughter when they die (Allen, Linn, Gutierrez & Willer, 1994; Martin, 2012). She wishes that her son had a partner in life but he thinks it unlikely due to his brain injury. She considers it important to show her son that he is loved as he has no partner to do this for him.

The family was told that Gordon would make progress with his ABI symptoms up to five years post-injury but Diana expresses that he is still making progress, in that if she helps him become familiar with a task he does eventually relearn it. However, this may involve Gordon becoming upset and raising his voice (BSRM&RCP, 2003), which the neighbours hear. Diana copes with this by explaining it as his frustration at the task, ‘Erm, well that isn’t because he’s being bad tempered. It’s because he’s frustrated.’ (3a/1404). She becomes upset at her neighbours’ lack of understanding of the symptoms of ABI and their perception of him is very negative (Tajfel & Turner, 1979). She sees them as thinking, ‘That means he’s not right in the head’ and because of their animosity she doesn’t get an opportunity to present Gordon any differently to them (Berger & Luckmann, 1966), ‘People just don’t understand. They just judge.’ (3c/6)

Diana anchors ABI with tragedy and ruining people’s lives (Berger & Luckmann, 1966), ‘It’s something you wouldn’t wish on your worst enemy’ (3a/1386). Yet
she sees a common positive disposition in people who have had a brain injury, when she attends an annual weekend meeting of the Headway Charity, ‘And they are the loveliest collection of people you'll ever wish to meet.’ (3c/28). She finds support through this social capital, ‘this is fantastic!’ (3c/22) (Bourdieu, 1986). She views this as being because they have all experienced adversity and survived, reformulating values, ‘And they realise erm, well, just how life, you know, that the things that bothered you before are really not important.’ (3c/46) (Frankl, 2004). Stigma is not an issue for this group of people, ‘they don't look at each other erm, as oddities.’ (3c/50), embracing what it is to be human and identifying the immorality of faultily reading an aesthetic (Frankl, 2004).

There are sometimes issues in managing Gordon’s social identity in a rural village where the community is small, ‘I mean he’s done some weird things’ (1a/129) (Deschamps & Devos, 1998; Conneeley, 2002). She sees the young people in the village as not understanding disability and see Gordon negatively as a result. However, she compares this favourably to city life, ‘Over here you’re more protected’ (3c/279), where she sees people with disabilities being susceptible to violence. The rural location brings with it restrictions to services such as transport and schemes Gordon could engage in such as gardening projects, which Diana knows exist in nearby towns, but there is little public transport (Leonard Cheshire Organisation, 2010).

In the present time Diana appears to have redefined her goals in terms of coping in order to establish the stable narrative she lives with today (Gergen & Gergen, 1986). She professes to not dwelling on the negative elements of life, ‘Never mind’ (1a/79). She identifies that she has many friends and also that she is a housewife, protective mother and gardener, ‘I love cutting lawns’ (3a/62), suggesting a pleasure in her engagement in occupations and roles (Csikszentmihalyi, 1993).

Diana’s occupational pattern exists around Gordon, her daughters and activities within the local community (Kielhofner, 2008). She still engages in a typical family division of labour and cooks and cleans for Gordon in her mother role (Hogg & Vaughan, 2014). She has a routine of activities she can engage with throughout the week in the local community, set around a pattern of doing daily living tasks for Gordon and then having trips with her younger daughter. She engages in a number of flow activities connected with nature, such as gardening
and carrying the theme of nature over to flower arranging and needlepoint. She also likes to knit for the flow experience rather than the end product (Csikszentmihalyi, 1993). She engages in some of these activities on her own, some with the other women of the village and then Gordon helps her with heavier duties around the house and garden.

She engages in solitary flow activities in her home, such as needlepoint and knitting, which she uses for relaxing, rather than producing an end point. She is neat and creative in these activities. She is also a keen gardener. She draws on an interest in nature that runs through many of her activities, such as the gardening and theme of her needlepoint and gifts from the family. She sees this as an inherited trait, which she has passed on to Gordon as well (in terms of a love of animals), with inheritance of identity being an important psychological organising principle (Castells, 2010).

Diana finds Gordon good company, being an elderly widow, ‘He’s there for company’, (3a/1066). She expresses how her son helps her when travelling, ‘Well he keeps me right when we go down on the train cos I’m a panicker’ (2b/69) and with heavy jobs around the house, ‘He’s good like that. He’ll do heavy digging’ (3a/122), thus fulfilling traditional family divisions of labour and roles (Hogg & Vaughan, 2014). However, she carries an underlying anxiety about the locus of control of Gordon’s behaviour and who will become his ‘centre point’ when she dies, wishing he could have a life partner, looking for resolution and harmony in Gordon’s life (Cashdan, 1999).

Overall, Diana’s occupational pattern is established and she is happy with it, thus her narrative is currently stable. Her main occupational role and occupational identity is that of a mother and she remains hugely protective of Gordon as part of this role. This is a role and identity that she has had since both before and after Gordon’s biographical disruption.
## Table 13: Thematic analysis table – Barriers and enablers to occupational engagement

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Enablers</th>
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<tbody>
<tr>
<td><strong>Symptoms of ABI and other health factors</strong></td>
<td><strong>Enablers</strong></td>
</tr>
<tr>
<td>1. Physical</td>
<td>2. Behavioural and cognitive issues</td>
</tr>
<tr>
<td>Mobility issues</td>
<td>Obsessive behaviour</td>
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<tr>
<td>Limited mobility</td>
<td>Disinhibited speech leading to social interaction issues</td>
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<tr>
<td>Hemiplegia</td>
<td>Emotional abuse</td>
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<td>Physical disability e.g. hemiplegia and mobility</td>
<td>Behavioural issues</td>
</tr>
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<td>Physical limitations e.g. mobility</td>
<td>Ritualistic behaviour and its management</td>
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<td>Physical disabilities e.g. mobility</td>
<td>Memory and face recognition</td>
</tr>
<tr>
<td>Fatigue x 5</td>
<td>Memory, sequencing, word finding, attention span</td>
</tr>
<tr>
<td>Auditory and visual hyper-sensory issues and changes to sense of taste</td>
<td>Memory, sequencing</td>
</tr>
<tr>
<td>2. Secondary health factors</td>
<td>Executive functioning</td>
</tr>
<tr>
<td>Epilepsy and low mood</td>
<td>Perseveration and loss of train of thought</td>
</tr>
<tr>
<td>Hair loss</td>
<td>Short-term memory and executive functioning</td>
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<tr>
<td>Hair loss, skin problems, physical pain, emotional lability</td>
<td>Demands of careful planning leads to lack of spontaneity</td>
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<td></td>
<td>Memory, prosopagnosia, sequencing</td>
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<td></td>
<td>Complete memory loss pre-ABI</td>
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<td><strong>Social capital, infrastructure and support</strong></td>
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<td><strong>1. Benefit system and finances</strong></td>
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<td>Secondary neurological condition</td>
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<td>Secondary diagnosis</td>
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<td>Terminal diagnosis</td>
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<td>SO’s own health status x 2</td>
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<td><strong>2. Social capital</strong></td>
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<td>Social capital, infrastructure and support</td>
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<td>Financial worries</td>
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<td>Poor administration of the benefits system x 3</td>
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<td>Financial issues</td>
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<td><strong>3. Specialist services for ABI</strong></td>
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<td>Lack of specialist statutory services x 4</td>
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<tr>
<td>Low investment in disability sports infrastructure</td>
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<tr>
<td>Lack of respite care</td>
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<td>Being placed in appropriate care e.g. for people with dementia</td>
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<tr>
<td>Racial prejudice of statutory service staff</td>
<td></td>
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<tr>
<td>Workplace unsupportive to disability issues</td>
<td></td>
</tr>
<tr>
<td>Exploited by government work schemes</td>
<td></td>
</tr>
<tr>
<td>Prejudice in the workplace and little adaptation</td>
<td></td>
</tr>
<tr>
<td>Environmental barriers to wife’s wheelchair</td>
<td></td>
</tr>
<tr>
<td>Medical model approach / attitude of medical and health professionals x 10</td>
<td></td>
</tr>
<tr>
<td>Health care staff dwelling on negative aspects</td>
<td></td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td></td>
</tr>
<tr>
<td><strong>1. Stigma in general</strong></td>
<td></td>
</tr>
<tr>
<td>Son being objectified by neighbour</td>
<td></td>
</tr>
<tr>
<td>Rejection by local community</td>
<td></td>
</tr>
<tr>
<td>Stigmatised by young people</td>
<td></td>
</tr>
<tr>
<td>Stigmatised in the workplace due to disability</td>
<td></td>
</tr>
<tr>
<td>Stigmatised re husband being unemployed</td>
<td></td>
</tr>
<tr>
<td>Stigma of injury to the brain x 2</td>
<td></td>
</tr>
<tr>
<td>Section</td>
<td>Description</td>
</tr>
<tr>
<td>---------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| 1. Stress and anxiety | Emotional distress / lack of sleep  
Feeling under constant stress  
Anxiety for the future  
Anxiety about coping in the future  
Anxiety about allowing paid carers to look after wife  
Anxiety about husband’s health, welfare and suicidal ideation  
Anxiety re possibility of husband’s volatile behaviour returning  
Worry about who will look after son in future  
Loss of health locus of control |
| 2. Guilt | About son having two ill parents  
About not being at home with husband  
About having trusted wife’s care to healthcare staff  
About how has treated parents due to her ABI in past |
| 3. Various other | Flatness  
Loss of affect |
| 2. Stigma from an invisible disability | Other’s lack of understanding  
Husband’s invisible disability  
Invisible disabilty x 2  
Being disbelieved  
Assumed drunk or more capable |
| 3. Social identity issues arising from stigma | Social identity issues / prejudice leading to social isolation  
Social identity issues x 4  
Impact of social skills |
| 4. Personal identity issues arising from stigma | Leaving behind the identity of being a healthy person  
Questioning own identity  
Loss of professional identity  
Changed identity issues due to revised marriage roles e.g. loss of driver role |
| **The emotional impact** | |

Stigmatised due to visual elements of facial paralysis  
Negative construction of disability  
Low status of disability sports  
Public perception of disability

Other’s lack of understanding  
Husband’s invisible disability  
Invisible disabilty x 2  
Being disbelieved  
Assumed drunk or more capable

Social identity issues / prejudice leading to social isolation  
Social identity issues x 4  
Impact of social skills

Leaving behind the identity of being a healthy person  
Questioning own identity  
Loss of professional identity  
Changed identity issues due to revised marriage roles e.g. loss of driver role

Emotional distress / lack of sleep  
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Anxiety about husband’s health, welfare and suicidal ideation  
Anxiety re possibility of husband’s volatile behaviour returning  
Worry about who will look after son in future  
Loss of health locus of control

About son having two ill parents  
About not being at home with husband  
About having trusted wife’s care to healthcare staff  
About how has treated parents due to her ABI in past

Flatness  
Loss of affect

Appreciates a greater being in the world.
<table>
<thead>
<tr>
<th>Strong urge to protect son</th>
<th>Fear of flying due to pressure on brain limits holidays</th>
<th>Doubts own self-worth</th>
<th>Suicide attempts</th>
<th>Depression</th>
<th>Jealous of dog receiving attention from husband</th>
<th>Endured catastrophic reaction to neuro-trauma</th>
<th>Disempowerment due to ABI</th>
<th>Husband’s lack of appreciation / becoming detached and aggressive</th>
</tr>
</thead>
</table>

**Rural living**

1. **Natural environment**

   - Close to nature
   - Love of nature
   - Tranquility helps cognitive issues
   - Tranquility helps sensory hypersensitivity
   - Flatness suits mobility issues

2. **Social capital, infrastructure and support in rural areas**

   - Limited social outlets x 2
   - Known. Local people prejudiced x 2
   - Limited local infrastructure
   - Limited transport x 4
   - Limited statutory services
   - Lack of specialist ABI services

   - Known. Local people understand son.
   - Known. Local people understand her disability.
   - Friendly community.
   - Better ABI services than urban area.
   - Having no neighbours reduces potential conflict.
   - Fewer people to reveal cognitive issues to.

**The impact on roles**

- Fatigue and cognitive issues led to losing worker and student role
- Has additional household tasks due to husband’s cognitive issues
- New driver role / loss of driver role

- Tried occupations wouldn’t have otherwise.
- Children more understanding
| Role conflict of being a manager of partner’s care and a spouse  |
|---|---|
| Paid carers in home takes away privacy / loss of opportunity for intimacy with wife |
| Fears losing independence in self-care |
| Lack of time for self x 2 |
| Sexual relationship issues |

<table>
<thead>
<tr>
<th>of disability.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has become a catalyst instead of a capitalist</td>
</tr>
<tr>
<td>Feels is answering a call from God.</td>
</tr>
</tbody>
</table>
### Table 14: Thematic analysis table – Strategies employed to cope with engagement in occupations due to ABI

#### Managing identity

| 1. Holding on to / presentation of an identity position | Presentation of self / loved one in a positive light e.g. highlighted strengths x 6  
Protects own identity as a care worker  
Justifies becoming unemployed by declaring a positive contribution over many years.  
Protects son’s social identity.  
Rejection of wife having a disability identity  
Rejection of carer identity in favour of wife identity  
Carries past worker identity even though no longer employed  
Manages social identity with local people by rejecting their sympathy |
|----------------------------------------------------------|
| 2. Comparison processes                                  | Compares own situation with others  
Rejects social signifiers of status  
Identifies with case studies in literature  
Takes inspiration from other people with disabilities |
| 3. Revealing / concealing disability status               | Guarded disclosure of disability status to minimise social identity issues and prejudice x 2  
Reveals disability status to explain behaviour |
| 4. Objectification / splitting                            | Considers difference as ‘normal’ as a way to view the marriage  
Separates ABI from sense of self  
Considers prejudice from local community as due to husband being different  
Sees self as ‘the Good Samaritan’ to continue to cope in difficult circumstances  
Labels health professionals as ‘good or ‘bad’ to differentiate  
Considers husband’s lack of affection as typically male  
Being recognised by family as someone who copes well |

#### Drawing on social capital

<table>
<thead>
<tr>
<th>1. Family</th>
<th>X 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Charities</td>
<td>X 7</td>
</tr>
<tr>
<td>3. Partner</td>
<td>X 3</td>
</tr>
<tr>
<td>4. Community / friends</td>
<td>X 3</td>
</tr>
</tbody>
</table>

#### Positively moving forward in life

<p>| 1. Zone of proximal | Encouraging wife to move out of zone |</p>
<table>
<thead>
<tr>
<th>Engagement</th>
<th>Moving self out of zone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Keeping to zone</td>
</tr>
</tbody>
</table>

2. The stalled plot
Rejecting the malaise from a stalled plot

3. Rehabilitation versus care
Identifying progress and rehabilitation
Setting goals x 2

4. Use of cognitive schema
Draws on occupational schema to move life forward
Seeing adversity as a romance to return people to a better state than before the tragedy
Seeing life as a journey

5. Acting with agency
X 6
Agency to achieve
Agency to challenge medical staff

6. Resilience
Looking past the problems and being pragmatic
Diligence and perseverance
Positive disposition
Being thankful for support and reciprocating
Viewing marriage as a partnership and accepting husband’s issues
Progression from stage of pre-injury self
Acknowledges own limitations
Normalisation of daily life

### Practical coping techniques

<table>
<thead>
<tr>
<th>1. Cognitive issues</th>
<th>Cue cards, diaries, making self aware of current affairs for conversation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Headphones + to reduce hypersensitivity</td>
</tr>
<tr>
<td></td>
<td>Lying to improve social skills</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Assistance</th>
<th>Paid help x 4</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>3. Therapy</th>
<th>Counseling</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physiotherapy</td>
</tr>
<tr>
<td></td>
<td>Vocational rehabilitation</td>
</tr>
<tr>
<td></td>
<td>Use of self affirmations</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Rural living</th>
<th>Less people to not recognise</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Tranquility helps hypersensitivity</td>
</tr>
</tbody>
</table>

<p>| 5. Occupational | Adapts husband’s life to meet his special needs |</p>
<table>
<thead>
<tr>
<th>Adaptation</th>
<th>Adapts employment to include husband as fellow worker</th>
</tr>
</thead>
</table>
| 6. Education | Researches own symptoms  
| | Self-help literature  
| | Informs self and presses for change |

**Adopting particular behaviours**

| 1. Ritualistic | Avoiding certain colours  
| | Excessive tidying to regain control |
| 2. Avoidance or distraction | Use of humour  
| | Escaping the family home  
| | Withdrew from working with people with similar diagnosis  
| | Taking time out  
| | Not dwelling on the past  
| | Denial |
| 3. Quest and altruistic behaviour | Creating a legacy  
| | Creating a legacy of a neuro-culture website  
| | Believes has left a positive legacy behind at work  
| | Creating opportunities for disabled people to be included  
| | Maintains a desire to help others and make progress  
| | Fighting for husband's rights  
| | Making an act of affirmation of love for wife  
| | Contributing to society by taking part in research  
| | Pursues a path of intrinsic reward |

**Engagement with spirituality**

| 1. Reification | X 3  
| | Placing self in hands of fate x 2 |
| 2. Superstition | X 1 |
| 3. Mindfulness | Living in the present time x 2  
| | Seeing biographical disruption as an opportunity for a greater appreciation of life  
| | Introvert characteristics – going inside own head  
| | Appreciating what time has left with loved ones |
### Appendix V

#### Table 15: Occupational aspects of the narratives

<table>
<thead>
<tr>
<th>Participant</th>
<th>Occupations</th>
<th>Persistent themes</th>
<th>Occupational identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 ABI</td>
<td>Reading – about famous people e.g. Brunel Sewing – American history figures or historical buildings Model-making – World War 2 figures Studying history. Visiting places of historical interest. Pets. Hospital treatment. Gardening. Holidays.</td>
<td>Solitary hobbies connected to history Supporting the under-dog and seeing realised potential (e.g. own education and rescue dogs)</td>
<td>Working class man. No professional past (factory and shop work). Under-achieved in education but aspired to be a history teacher.</td>
</tr>
<tr>
<td>Participant</td>
<td>Occupations</td>
<td>Persistent themes</td>
<td>Occupational identity</td>
</tr>
<tr>
<td>------------</td>
<td>----------------------------------------------------------------------------</td>
<td>--------------------------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td>Participant</td>
<td>Occupations</td>
<td>Persistent themes</td>
<td>Occupational identity</td>
</tr>
<tr>
<td>------------</td>
<td>-----------------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>11 SO</td>
<td>Gardening. Community involvement. Engaging with son in shared occupations. Shopping with daughter. Crafts e.g. knitting, needlepoint, flower arranging.</td>
<td>Mothering occupations.</td>
<td>Mother</td>
</tr>
</tbody>
</table>