

## **The Experience of Living with Adult-Onset Epilepsy**

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## Abstract

The incidence and prevalence of adults diagnosed with epilepsy is higher compared to those diagnosed in childhood, yet the experience of living with adult-onset epilepsy has rarely been examined. Hence, the current study took a phenomenological approach to examining the experience of living with epilepsy following diagnosis in adulthood. Semi-structured interviews were conducted with 39 people from across the UK, diagnosed with epilepsy between the ages of eighteen and sixty, at two points in time, six months apart. Phenomenological analysis identified three central themes: the unpredictability of seizure occurrence; the ripple effect; and re-evaluating the future. Despite the accepted consensus in the epilepsy literature that living and coping with epilepsy becomes more difficult the older a person is diagnosed, the current findings indicated that this is inadequate. Rather, it is more suitable to consider that those living with adult-onset epilepsy have a specific experience of the condition and particular support needs, given that they once lived their lives as people without epilepsy.

## Keywords

Epilepsy; Adult-Onset; Experience; Phenomenology; Qualitative; Unpredictability

## Highlights

- The impact of adult-onset epilepsy requires further investigation in its own right.
- Periods of seizure freedom can be a cause of anxiety for PWE.
- The impact of adult-onset epilepsy can be observed across all aspects of life.
- Interference of adult-onset epilepsy with plans for the future can be problematic.

## 1. Introduction

Although epilepsy is one of the most common long term neurological conditions in the UK [1], the lived experience of this illness has received relatively little research attention. Furthermore, although epilepsy prevalence increases with age [2], adult-onset epilepsy is rarely examined. Indeed, a small number of studies have identified 'age at onset' as a predictor of quality of life (QOL), with 'older age at diagnosis' correlating with poor QOL [3, 4, 5]. Certainly Chung et al. [6] identified that people with epilepsy (PWE) diagnosed later in life coped poorly with the diagnosis, whilst those diagnosed earlier in life displayed "emotional hardiness" (p. 258). Additionally, despite some studies reporting findings from adult populations, there is inconsistency within samples with regards to whether they were diagnosed in adulthood, hence an examination of the experience of living with adult-onset epilepsy is necessary.

A comprehensive range of psychosocial variables, including self-esteem [7, 8] emotional functioning [9, 10] and social functioning have been found to negatively affect PWE in general, in populations across the UK and Europe [11], America [12], the Middle East [13], China [14] and parts of Africa [15]. However, the focus often centres around an examination of seizure-related variables. Indeed, seizure frequency and severity appear to be the most significant predictors of QOL [16, 17, 18], with high seizure frequency significantly correlated with poor QOL scores [19, 20, 21], with this observation reversed when seizure frequency decreases [22, 23]. Furthermore, a number of seizure-related variables have been correlated with broader psychosocial concepts, such as seizure severity and social functioning [24] and the perception of stigma and seizure worry [25].

There is also a wealth of literature examining depression and anxiety in PWE. With one in three PWE experiencing depression, it is the most common comorbid psychiatric condition in PWE [26] and there is certainly considerable evidence that anxiety and depression are significantly associated with poor QOL [19, 27, 28], as well as predictors of QOL in PWE [29]. Although attempts to examine what moderates this relationship predominantly focus on seizure occurrence [30, 31], Kwon and Park [32] found that one fifth of PWE who were seizure free for at least

one year exhibited symptoms of depression, indicating that seizure occurrence is not the sole mediator of the relationship between epilepsy and mental health problems.

Nevertheless, there appears to be a bias in the current literature in favour of reducing the impact of epilepsy down to seizure occurrence. Furthermore, this evidence tells us little about the lived experience of PWE. Additionally, much of this research is quantitative in design (particularly QOL designs). Arguably, adopting such a positivist position only serves to isolate specific variables which may not be of importance to PWE in their broader illness experience [33] and limits how we see PWE making sense of their illness within their social worlds [34]. Furthermore, the complete epilepsy experience cannot be explored in depth [35]. Consequently, a qualitative approach is advocated to provide the opportunity to explore the meaning of the phenomena for the person and better understand their experience [36, 37]. Kugelmann [38] regards illness as an experience, a mode of existence or “being” (p. 75), hence a qualitative approach will allow in depth exploration of the meaning of “being” ill, or in this case, “being” a person diagnosed and living with epilepsy.

Research which examines living with epilepsy has previously been advocated [39], whilst a review of current qualitative research by Rapport, Clement, Doel and Hutchings [40] highlighted the effectiveness of adopting a lived experience approach to epilepsy. A systematic review of qualitative research examining the impact of the condition on children and adults [41] highlighted concerns over the unpredictability of seizure occurrence, issues with employment and finances, relationships, independence and self-esteem. However, the depth of analysis was limited. Indeed, many of the qualitative studies continue in a similar vein as those adopting a quantitative approach; categorising their findings in relation to known concepts and thus failing to add further depth to their interpretations [42, 43, 44]. Certainly, Nijhof [45] cautioned that such categorisation will only lead to homogeneity in the research findings and limits our understanding of the epilepsy experience.

Indeed, a qualitative approach allowed Faircloth [46, 47] to examine contradictions in accounts, such as the ways in which PWE originally commented on their ability to control seizure occurrence, whilst later discussing the overwhelming force of a seizure and the ultimate difficulty they had in preventing a seizure from occurring.

Furthermore, Jacoby, Ring, Whitehead, Marson and Baker [48] identified the central role of loss in the experience of PWE, be it loss of confidence, independence or control, amongst others. Additionally, seizure control was found to be central in reducing loss, particularly through the way in which it increased the confidence of PWE and helped them to feel “normal” again. Finally, a recent narrative analysis of the exercise experience of people with epilepsy has highlighted the ways in which the condition interferes with their exercise routine on a daily basis [49].

However, qualitative epilepsy research predominantly focuses on specific issues, such as loss [48] or exercise experience [49], rather than the broader lived experience of epilepsy. Nevertheless, studies such as these demonstrate how choosing a qualitative approach to examine the experience of living with epilepsy can provide more insight into the condition than research has delivered to date. Certainly, focusing on the illness experience within a qualitative framework can allow examination of the relationship between the body, self and society [50, 51].

Consequently, a phenomenological approach is advocated in order to produce an in-depth analysis of the meaning of living with adult-onset epilepsy [52, 53] and produce rich descriptions of the experience [54]. A phenomenological epistemology can provide the opportunity to move beyond the mind-body dichotomy and can bring meaning to the study of health and illness, since it conceptualises “being in the world” (p. 10) [55] as an embodied phenomenon. Furthermore, this approach places participants in the centre of the illness experience; recognising them as the experts on the condition [56, 57]. Hence, the current study aimed to explore the experience of living with adult-onset epilepsy.

## 2. Method

### 2.1. Design

Semi-structured interviews were conducted to allow participants to recount their story in their own way, whilst also allowing the researcher to probe areas of interest raised throughout each interview [53]. Six months later, following initial analysis, follow-up interviews were conducted with willing participants. This strategy allowed time to reflect on areas of interest emerging from the first interviews and examine these in

more depth [58, 59], as well as providing an opportunity for prolonged engagement in order to enhance the credibility of the research [60].

## 2.2. Participants

Participants were recruited through an advert placed on the Epilepsy Action website and newsletter. A further three were recruited from a support group in the North East of England. Interested parties were asked to contact the lead researcher (SK) to ensure they met the inclusion criteria. Firstly, they were required to have been diagnosed with epilepsy between the ages of 18 and 59 years old. This ensured that participants were only able to access adult healthcare services at diagnosis, since older adults could arguably have a different healthcare experience given the increasing recognition of their specific clinical and psychological needs [61].

Secondly, participants were required to be taking antiepileptic medication at the time of recruitment, since PWE who have successfully withdrawn from their medication would arguably have a different experience of the condition than those who are currently experiencing seizures or living with the threat of seizure occurrence [62]. No further restrictions were placed on the sample.

Thirty-nine participants were recruited in total (14 men and 25 women). They were diagnosed with epilepsy between 18 and 57 years of age, with an average age at diagnosis of 31 years. Duration of epilepsy ranged from 1 to 49 years (15 years on average). Additionally, 76.92% of participants were diagnosed with idiopathic epilepsy, with the remaining participants having developed epilepsy as a result of either a brain hemorrhage (7.69%), encephalitis (5.13%), head injury (7.69%) or a brain tumor (2.56%).

The majority of participants (84.61%) reported experiencing generalised seizures, with six (15.39%) having experienced focal seizures. However, 13 participants (33.33%) reported that they had not experienced a seizure for up to 30 years (eight and a half years on average) and one of whom was controlled immediately from diagnosis. The remaining 26 participants continued to experience seizures during the study period, meaning that they had experienced seizures for between 1 and 37 years (almost 14 years an average). Additionally, for those participants who were experiencing seizures during the study period, the majority experienced them on a

weekly or monthly basis, although some could experience seizures on a daily or even a yearly basis. However, many participants did report variation in the frequency of seizure occurrence.

Finally, 24 of the original 39 participants consented to take part in a follow up interview (6 men and 18 women). The demographic details were largely comparable across the first and follow-up interviews (see table 1). The 15 participants who chose not to take part in a follow-up interview, exerted their choice by not replying to either the email or letter sent by the lead researcher which requested their participation in a second interview.

INSERT TABLE 1 HERE

### 2.3. Materials

Two interview schedules were designed. The first adopted an episodic approach to contextualise living with epilepsy, by asking similar interview questions in relation to different time points (life before, during and since diagnosis) [63]. Questions were open and non-directive, to allow participants to discuss experiences relevant to them [36]. However, since it is argued that the wording of open questions can be leading and demonstrate researcher bias [45], specific topics were avoided in favour of broader questions exploring the lived experience, such as, “tell me about life before you were diagnosed” and “what does having epilepsy mean to you?”. The follow-up interviews then became more directional in order to probe key issues further, such as identity, independence, stigma and control. Examples included, “talk me through anything that changed in your life when you were diagnosed” and “how would you describe somebody with epilepsy?”. Additionally, demographic questions were asked during the first interview.

Following the first three interviews, the recordings were transcribed and reflected upon in terms of the appropriateness of the questions. This reflection was also carried out following the first three follow-up interviews. As a result of these reflections, no changes to the interview schedules were deemed necessary.

### 2.4. Procedure

Following ethical approval from Teesside University Ethics Committee, the interviews took 20 months to complete and ranged between 35 and 50 minutes in duration. All interviews were conducted by the lead researcher. Although some participants either attended the University campus for their interviews or they were conducted at their home, telephone interviews were the dominant mode of data collection; specifically, 74.36% of the first cycle of interviews (29 participants) and 83.33% of the follow-up interviews (20 participants). Although Miller and Glasner [64] argued that rapport is the key to successful interviews, the telephone interviews did not appear to hinder the development of a rapport between the participant and researcher. Indeed, they often lasted longer than those conducted face-to-face, perhaps due to the enhanced anonymity of the participant [65].

Data saturation was achieved by interview thirty, as no new data emerged from the interviews. However, since people continued to volunteer for the study, it was decided to continue with recruitment to ensure that the diversity of the sample did not impede the analysis.

## 2.5. Analysis

All interviews were anonymised through the use of pseudonyms, transcribed and analysed by the lead researcher using Moustakas' [66] method, whereby significant statements regarding the experience were identified in each transcript (the process of horizontalisation) before clustering these statements into themes. Since this method did not require initial theme ideas to be developed following analysis of each individual transcript, it was felt that this strategy reduced potential bias, as the researcher did not have any preconceived theme ideas when identifying significant statements in later transcripts. Additionally, a reflexive diary was completed by the lead researcher throughout the research process [67].

Initially, horizontalisation was conducted on all of the transcripts from the first interviews and key issues were identified in order to develop an interview schedule for the follow-up interviews. However, no theme generation was conducted at this point to limit the potential for bias in the analysis of the follow-up interviews. Once horizontalisation was completed for the follow-up interviews, clustering of all

significant statements from both interview cycles was conducted to produce the final themes.

### 3. Results

Three main themes were identified from the analysis; namely, the unpredictability of seizure occurrence, the ripple effect, and re-evaluating the future.

#### 3.1. Theme one: The Unpredictability of Seizure Occurrence

It was evident that regardless of seizure frequency, the sudden, unpredictable occurrence of a seizure was a concern for the participants.

But I still have the same old problem I'm afraid and that's never going to go away. It's so erratic, you can't say from one day, everything's going hunky-dory and then bang...

Jonathan, Int.2; lines.7-9; uncontrolled

...it's like a kick in the teeth and it does dent your self-esteem to the point where you start thinking "I can't do this" and "I can't do that". I think, you know, you're just frightened to do it more than anything else, just in case you set anything off again.

Janet, Int.1; lines.268-272; controlled

I still get panic attacks now, thinking about it [seizures] and sometimes I'm just sat in the house with the wife, and now I feel my arm doesn't feel right, and my wife looks at me and says "calm down, just relax". ... that's the worst thing, the uncertainty.

Peter, Int.1; lines.113-119; controlled

The way in which Jonathan used the word "bang", as though the seizure hit him unexpectedly, emphasised the impact of seizure uncertainty. Certainly, Jonathon experienced variability in seizure frequency; recounting instances where he would experience no seizures for weeks or months, followed by a cluster of seizures over a number of days. Accounts such as this also highlight the lack of control which PWE have over seizure occurrence. Participants referred to the fact that this uncertainty lived with them daily: lurking in the background of their lives; which they had no control over. Furthermore, although both Janet and Peter reported that their seizures had been controlled for nine and three years respectively, they both discussed how

the uncertainty of seizure occurrence was a concern. Certainly, despite a nine-year period of seizure freedom, Janet discussed how the unpredictability of seizure occurrence still affected her confidence in carrying out different tasks and ultimately her self-esteem. Indeed, PWE discussed restricting activity to limit the impact of seizure occurrence.

We did like to go walking, we were getting more and more adventurous, but I was getting all the time where I was losing my confidence because I was thinking, if you go here, like anything can happen like if its on a dodgy bit when you're climbing, its just always in the back of your brain, what happens if?, you know, its just like that all the time, and now I've got where I won't even go, I'll go only if its a flat walk, 'cos I have had a couple (of seizures) when I've been walking, I just get so edgy about things.

Sharon, Int.2; lines.251-258; uncontrolled

Well it's changed in a way like I say because of the fits. I could be outside, I could be anywhere. I could take a fit. But like I say, if I take one in here [at home], in a way I feel safe. 'Cos even though the door's locked it might, this sounds silly, even though the door's locked, I know I can't get out. 'Cos once you get out there, scares you. All the cars and that y'know bippin an this 'cos I don't know what they are.

Chris, Int.1; lines.185-190; uncontrolled

The possibility of having a seizure at any moment was constantly in the thoughts of the participants. Central to this concern was the fear of injury and worry for their safety; even leaving the house could be a problem considering seizure uncertainty. Consequently, for some, periods of seizure remission were viewed positively. However, for many, periods of seizure freedom could be more concerning, as they waited for the next seizure to occur.

That has happened where I've gone eighteen months maybe two years whatever, without a seizure, and you've thought oh great you know, things are looking up and maybe one day we can talk about reducing medication, that sort of thing, em...but there's also, a slight, you know, sort of somebody on your shoulder thinking, you know, things might be building up for you to have another seizure. When they reoccur, it's destroying, soul destroying...em, it's, you're very emotional, very tearful, because you know that you've gone such a, a long period. It's like a snake on a snakes and ladders (board), you've got so far and then the snakes come along and you just start back from scratch.

Judy, Int.2; lines.201-211; uncontrolled

Yeah, I mean, I, as I say have them about three or four times a month for me, and you're just waiting for it to happen, you know you think it's gonna happen sometime now 'cos it always does. But when it does happen I get really upset, because I think oh you know I was doing well and now I've stepped back again...

Kirsty, Int.2; lines.89-93; uncontrolled

A continuum of seizure remission became evident, whereby participants felt they had moved forward in their lives during times of seizure freedom and reverted to the beginning of the continuum once a seizure had occurred. It was interesting that it was not necessarily increased seizure frequency which had the most profound effect on the participants, rather, that longer periods of remission allowed the participants to move further along the continuum, only to return "back" (Kirsty Int.2; line.93) once a seizure had occurred. For example, experiencing a seizure after a period of seizure freedom which lasted for over 18 months, had a profound psychological effect on Judy. Indeed, a period of seizure freedom represented an opportunity to look to the future.

I was, going back to my time there, I was having the time of my life there, and I thought I was really achieving something, and I absolutely loved the life, everything seemed to be going hunky-dory then BANG [claps his hands], over night, I thought it's done it again. Although I try to not let it happen, it does impinge on what I want to be able to do, and so I get very frustrated with it...

Jonathan, Int.1; lines.293-299; uncontrolled

The other big thing about it is you can't drive. That's the other thing for me, yeah, 'cos I mean I can't walk very far so a car was like me lifeline, er, and once I was diagnosed that was the end of it. So I keep hoping, you know, like a, maybe twelve days since I've had one and I think oh great, you know, and then I'll have one and I'm back to a year again, so, it gets pretty upsetting really.

Kirsty, Int.2; lines.50-56; uncontrolled

Participants reflected on how life could move forward during times of seizure remission, indicating that they felt unable to work towards accomplishing future aspirations during times of regular seizure occurrence, causing upset and frustration.

### 3.2. Theme two: The Ripple Effect

An issue raised repeatedly during the interviews was the broader impact of epilepsy on participants' lives, illustrating how living with epilepsy could revolve around more than seizure occurrence. Comments such as "life changing" (Michelle Int.1; lines.71-72) highlighted how an epilepsy diagnosis in adulthood could have an impact on all areas of life.

I was, you know, a bad case, and that's it, that's it to them. I mean, I had a life. I was supposed to have a life...

Louise, Int.1; lines.100-101

It was a disaster actually. Lost my car, so I lost my job and then my accommodation came with my job, so I lost my accommodation as well.

Sue, Int.1; lines.35-39

Ah, it was strange em, because everything sort of changed, I sort of, I lost me heavy goods licence, I lost me car licence, I lost me job, em...It was, it was so surreal, it was weird, I, I couldn't describe it. ... just...weird...devastation. I'd lost everything, everything I, you know, I had a job I loved, em...I'd been, you know, been in the particular job for er, I'd been doing for sixteen years em, and everything was gone.

Peter, Int.1; lines.75-84

A ripple effect was clearly observed which stemmed from the diagnosis, outwards towards different areas of life. For many, this began with the loss of their driving licence and this was certainly one of the first issues raised when asked what it meant to live with epilepsy. However, the underlying problem seemed to be a loss of independence and the inability to choose the activities they wished to engage in.

Well it is [restrictive] isn't it, because I'm not allowed a shower unless my husband's in the house, and baking, and cooking with hot stoves...I mean I'm beginning to do that now under supervision.

Sarah, Int.2; lines.138-140

I have certain problems, like physical problems, but nothing was like having epilepsy. Erm, but before that, you know, I could go out by myself. I could go away and have a bath by myself and do some cooking and things like that, which I can't do now. So basically that's what's changed in my life really.

Kirsty, Int.1; lines.2-7

Being unable to undertake everyday activities, such as having a bath or cooking without supervision became concerns for PWE and led to feeling restricted by the

condition. The unpredictability of seizure occurrence limited what PWE could do in the world during seizure-free periods. This was further compounded by the fact that they once lived as adults without epilepsy; as independent adults, able to engage with these activities without giving it a second thought. However, Sarah described herself as “not allowed” to have a shower or cook on her own, whilst Kirsty reflected on activities which she “can’t do now”, implying these restrictions have been imposed upon them externally (perhaps by their family or following advice from medical professionals). Conversely, some PWE rejected these restrictions.

..the neurologist said about the certain things that you shouldn't do, you shouldn't climb trees, erm, ride a bike, erm...oh like have a bath or a shower when you're in the house on your own, but I mean I do have showers when I'm in the house on my own... if I get up in a morning and I em, and I feel absolutely a hundred per cent fine I think oh well, I chance to have a, I mean maybe I shouldn't have the shower if I'm here on my own but, you have to sort of, you have to live your life really, you know you just have to sort of get on with it really I think sometimes.....I never ever used to, but as time's worn on I think oh I'll just, you know I'll just do it and, like I say sometimes I just completely forget about the fact that I am epileptic. It's only afterwards when I've done something that I think oh, perhaps I shouldn't have done that, but...so...So I would say yes, it is restrictive in some...in some aspects, definitely.

Helen, Int.2; lines.158-178

...It's more the restrictions that other people put in it, you know, there's a lot of people that say, if you've got any of these conditions then you can't do, and you think well why can't I?

Rachel, Int.2; lines.86-88

Some PWE made a conscious decision not to allow epilepsy to prevent them from engaging in various activities. However, it is important to note that these participants had lived with epilepsy for between three and eighteen years and hence, the ability to achieve this may have developed over time. As an extension of this, some reflected on the ways in which they learnt about their condition in order to continue to partake in various activities.

I've got to know my own limitations, em, that's very important I think with anybody who has epilepsy. It shouldn't stop you doing everything but you've got to be aware of things, if I do that you're asking for trouble basically...You've just got to be aware of it, you've got to take it into account. As long as you do that sensibly, there's no reason why you can't get more out of life.

Alistair, Int.2; lines.166-171

I just have to get my head around the fact that this is it, and also work out what strategies, if any, I need to put into place, and sometimes that takes quite a while.

Hannah, Int.2; lines.67-70

Learning about their own particular experience of epilepsy, allowed PWE to engage in activities which they may otherwise have felt unable to undertake. Learning about their own epilepsy, their triggers and the strategies to put in place to deal with the condition could make PWE more confident and able to maintain a balance between what they want from life and maintaining their safety. In these ways, it can be suggested that participants were attempting to retain a level of control over their lives. However, Hannah described having to “get my head around the fact that this is it” (Int.2; line.67), implying that there remains an element of adaptation and coming to terms with her new life, involved in learning about the condition; learning how epilepsy affects one specifically is not a simple task and can take time.

### 3.3. Theme three: Re-Evaluating the Future

Having epilepsy was not always reflected upon in negative terms. Certainly, some participants described how their lives had changed for the better as a result of re-evaluating their future plans in light of their epilepsy diagnosis.

...and I'm aware of the job that I've lost, but then equally there's things that I've gained. It's actually nice to be in when me daughter comes in and it's nice to have the dog and be able to help others and things like that, so there are pluses, I'm not dashing out the door and things like that.

Rachel, Int.2; lines.154-158

I mean, a lot of good things have come out of it. I've got to say. It's probably secondary, but I probably wouldn't have gone to University if I hadn't had epilepsy.....No way, and still be in a job I liked, but I didn't want to do for the rest of my life. It's not all miserable at all.

Sue, Int.1; lines.228-236

It would be inappropriate to assume that living with epilepsy could not be positive, since these participants adapted their future plans with positive outcomes. In some cases, such as Sue, these plans had always been aspirations but the safety of previous circumstances prevented them from making any changes in their lives.

However, when the diagnosis of epilepsy disrupted life as they knew it, some had nothing more to lose. However, for others, the impact on future plans was not met so positively.

Er, I feel a lot aggrieved, and I feel misunderstood, because when you're a young chap you think, get married, have a family, er go to work, come away from work, and you want to do the normal, and you feel like you're robbed because there are a lot of jobs I could do, a lot of jobs. I wanted to do that, I was stopped...I was even stopped from er, joining the army, because they said that if they put me in a jeep and I had a fit, or left behind a gun and I had a fit, so there were a lot of things I found out that I couldn't do.

Patrick, Int.1; lines.145-152

...so it didn't stop me from what I wanted to do, but I suppose it made me restrict myself in what I could do. And...it sort of I think, mid to late twenties, it's the time when things should be happening and maybe they didn't necessarily happen because of that, so my life took a different journey than maybe other people's lives did. You know, I didn't settle down and have children, that sort of thing, because of my partner, because of my epilepsy.

Judy, Int.2; lines.181-187

PWE with established plans commented upon the way in which epilepsy interfered with the course their life took. Again, this can be particularly pertinent to adult-onset epilepsy since the timing of onset may coincide with instigating particular plans, such as starting a family in Judy's case. However, she reconciled this by readjusting her goals for the future, commenting that epilepsy did not stop her from engaging in various activities, it only restricted what she could choose to aspire to. Alternatively, PWE found it easier to accept the condition if they either had no established plans for the future or had already achieved their goals.

Ok I couldn't join the army, but it's not something I ever hoped to do, so if there was something, if I had wanted to do that or join the police and stuff like that, then I think it would be a lot more difficult to accept that there are some things I can never do.

Jane, Int.2; lines.46-49

It obviously for younger people can seriously affect the employment they can get, jobs they can do. In my case it didn't happen 'til I was retired er, so you know, its not important for me is it?

John, Int.2; lines.92-95

Participants diagnosed earlier in life (such as Jane, aged twenty), before they had established clear goals for the future, were able to readjust their plans to adapt to the epilepsy diagnosis. On the other hand, the participants diagnosed later in life, such as John (aged fifty-seven), when they had fulfilled their ambitions, felt that they had lived a good life, having many years without epilepsy. Consequently, central to this theme was the way in which participants re-evaluated their lives in the context of the condition.

#### 4. Discussion

The three themes demonstrate how the unpredictability of seizure occurrence is central to the experience of living with adult-onset epilepsy. The fact that some participants experienced panic attacks at the thought of having another seizure, highlights the profound impact of the uncertainty of seizure occurrence on the emotional wellbeing of PWE and contradicts the literature which would propose that seizure control would lead to improved psychosocial outcomes for PWE [19, 20, 22, 48]. This finding illustrates that the dominant focus in the epilepsy literature on examining seizure frequency in relation to a variety of psychosocial variables is insufficient to enable us to understand the experience of living with the condition.

Certainly, Kerr et al. [41] identified seizure unpredictability as a concern for PWE, however, it could be argued that it impacts upon the experience of living with adult-onset epilepsy on a daily basis. In particular, participants all discussed the way in which a diagnosis of epilepsy produced a ripple effect which moved throughout their lives and could restrict their engagement with certain activities, such as driving, working, exercise, cooking and even taking a bath. Furthermore, these restrictions were often predicated on the unpredictability of seizure occurrence. Additionally, these restrictions can be particularly problematic for those with adult-onset epilepsy, since they were once able to engage in these activities and live a more independent life. Indeed, previous research has identified the negative impact of epilepsy on social functioning [24], as well as restrictions on employment [41] and engaging in activities such as exercise [49]. However, the dominant research strategy of examining specific issues in isolation or in the context of QOL constructs, is narrow in focus and fails to produce a holistic conceptualisation of the impact of living with

adult-onset epilepsy. Consequently, exploring specific issues of concern to PWE means that researchers have overlooked the underlying problem for PWE: the impact on daily life which results from an epilepsy diagnosis.

Some PWE discussed learning about and understanding their own particular epilepsy experience, in order to regain some control over the activities they could engage in, reflecting a form of self-management. Indeed, the National Institute for Health and Care Excellence [68] advocate self-management as a means of empowering PWE by developing an increased understanding of the condition.

Conversely, periods of seizure freedom can represent recovery from epilepsy and can be a source of hope for some PWE. They feel they are moving forward, engaging in activities and moving towards a life where they are once again able to engage in various social activities, such as driving and reengaging with employment opportunities. However, when a seizure occurs, it returns them to the beginning of the journey. What was interesting was the way in which this occurred regardless of the length of time without a seizure (for some the journey started straight after their last seizure), although this served to make PWE fear seizure recurrence, meaning that even periods of seizure freedom could be a source of anxiety. Indeed, Kwon and Park [32] reported how PWE can experience anxiety and depression when seizure frequency is reduced and certainly the current findings suggest that this may be due to their concern over seizure recurrence, as a result of the unpredictability of the condition. The concept of biographical disruption [69] is based on the way in which a diagnosis of chronic illness can interfere with a person's biography, yet if we apply this concept to adult PWE, it appears that a form of biographical disruption can occur each time a period of seizure freedom comes to an end. Consequently, the incorporation of psychological services in the care pathway for adults living with epilepsy is advocated. Allowing adults with epilepsy the opportunity to access appropriate support services or therapeutic interventions throughout their illness trajectory could facilitate PWE in coming to terms with the unpredictability of seizure occurrence.

Moreover, the age of the participants did not necessarily affect the way they dealt with the diagnosis; rather participants experienced difficulty in coming to terms with

their condition if it directly interfered with their plans for the future. As such, participants who were diagnosed later in life but who had achieved their life goals (be those personal or professional), felt lucky that they had been able to live without epilepsy for so long. Yet those who still had plans to fulfil for the future felt that epilepsy had prevented them from achieving these aspirations. On the other hand, participants diagnosed in early adulthood without definitive plans for the future did not reflect on the impact of epilepsy as negatively as those who had their future mapped out and felt that epilepsy would interfere with these plans. Although the epilepsy literature considers how those diagnosed with epilepsy at an older age experience more difficulty in coping with their condition than those diagnosed at a younger age [6], the current study demonstrates that it is the impact on established life goals, regardless of age, which is problematic for people with adult-onset epilepsy. Again, this is reminiscent of the concept of biographical disruption [69] and could be a further target for support services which would facilitate adjustment to adult-onset epilepsy.

However, not all of the experience was negative, with some PWE discussing the opportunities which became open to them following diagnosis, yet there is an underlying sense in the chronic illness literature that people with chronic conditions are suffering and experiencing loss [70]. Indeed, Jacoby et al. [48] also focused on loss as being central to the epilepsy experience.

Consequently, these findings promote the recognition of the individual nature of epilepsy. Variation in the experience of epilepsy is not necessarily associated with seizure severity or occurrence, age at diagnosis, cause of epilepsy or seizure type. Certainly, although the unpredictability of seizure occurrence was indicative of the experience, living with adult-onset epilepsy was conceptualised as far more than seizure occurrence; a ripple effect was clearly observable in the way in which the epilepsy diagnosis had a knock-on effect onto various aspects of participants' lives. As such, broader support is required for adult PWE to come to terms with the impact of their condition and the potential far-reaching consequences of an epilepsy diagnosis.

However, there were several limitations to the current study. Firstly, the sample of PWE in the current study was extremely broad, with variations in the cause of epilepsy, seizure type and duration of epilepsy. Although this approach was considered necessary given the paucity of research examining the experience of living with epilepsy, a more targeted approach to sampling in future research would allow more detailed examination of key findings. For example, the experience of PWE whose seizures are controlled could be examined in its own right, with a particular focus on their journey towards seizure control and the initial period of seizure remission. Furthermore, some participants had lived with epilepsy for up to thirty years, hence, their experiences may not be relevant to adults recently diagnosed with epilepsy. Although, similar issues were also evident in the newly diagnosed participants in the sample, closer examination of those recently diagnosed is recommended.

Nevertheless, this is the first study, to our knowledge, which examines the lived experience of adult-onset epilepsy. For future research, it would be useful to engage with participants from the time of diagnosis and follow their journey for a period of time, rather than the range of illness trajectories included in the present study. This would also enable the impact of diagnosis in adulthood to be examined in more detail, with a view to establishing appropriate support services for those diagnosed in adulthood. A qualitative approach would continue to be advocated to these future research strands, since it allows for a more holistic exploration of the experience [71]. As such, further research would contribute to the establishment of a sound evidence base to develop support strategies for people living with adult-onset epilepsy.

## 5. Conclusions

Epilepsy research, be it quantitative or qualitative, tends to atomise aspects of the epilepsy experience by focusing on specific issues. This study has demonstrated that the experience should be examined more holistically, in order to examine issues in more depth and uncover new insight. Furthermore, when examining adult-onset epilepsy specifically, we must take into account the person's life, biography and

aspirations prior to diagnosis in order to effectively support them to live with the condition.

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### References

- [1]. Booth L, Thompson G. Epilepsy Statistics. London: House of Commons Library; 2010.
- [2]. Joint Epilepsy Council of the UK and Ireland. Epilepsy Prevalence, Incidence and Other Statistics. London: Author; 2011.
- [3]. Loring DW, Meador KJ, Lee GP. Determinants of quality of life in epilepsy. *Epilepsy Behav* 2004;5:976-980.
- [4]. Mollaoglu M, Durna Z, Dener S. Quality of life in people with epilepsy in Silvas, Turkey. *Neurol Psychiat Br* 2004;11:189-194.
- [5]. Zhao Y, Zhang Q, Tsering T, Sangwan Hu X, Liu L, Shang H, Chen Q, Liu Y, Yang X, Wang W, Li S, Wu J, Sander J, Zong D. Prevalence of convulsive epilepsy and health-related quality of life of the population with convulsive epilepsy in rural areas of Tibet Autonomous Region in China: An initial Survey. *Epilepsy Behav* 2008;12:373-381.
- [6]. Chung K, Liu Y, Ivery SL, Huang D, Chung C, Guo W, Tseng W, Ma D. Quality of life in epilepsy (QOLIE): Insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). *Epilepsy Behav* 2012;24(2):256-263.
- [7]. Giray S, Ozenli Y, Ozisik H, Karaca S, Aslaner U. Health-related quality of life of patients with epilepsy in Turkey. *J Clin Neurosci* 2009;16:1582–1587.

- [8]. Piazzini A, Ramaglia G, Turner K, Chifari R, El Kiky E, Canger R, Canevini MP. Coping strategies in epilepsy: 50 drug-resistant and 50 seizure-free patients. *Seizure* 2007;16:211-217.
- [9]. Nubukpo P, Clement JP, Houinato D, Radji A, Grunitzky EK, Avode G, Preux PM. Psychosocial issues in people with epilepsy in Togo and Benin (West Africa) II: Quality of life measured using the QOLIE-31 scale. *Epilepsy Behav* 2004;5:728-734.
- [10]. Pugh MJV, Copeland IA, Zeber JE, Cramer JA, Amuan ME, Cavazos JE, Kazis LE. The impact of epilepsy on health status among younger and older adults. *Epilepsia* 2005;46(11):1820-1827.
- [11]. Buck D, Jacoby A, Baker GA, Ley H, Steen N. Cross-cultural differences in health-related quality of life of people with epilepsy: Findings from a European study. *Qual Life Res* 1999;8:675-685.
- [12]. Leidy NK, Elixhauser A, Vickrey B, Means E, Willian MK. Seizure frequency and the health-related quality of life of adults with epilepsy. *Neurology* 1999;53(1):162-166.
- [13]. Baker GA, Jacoby A, Gorry J, Doughty J, Ellina V. Quality of life of people with epilepsy in Iran, the Gulf and Near East. *Epilepsia* 2005;46(1):132-140.
- [14]. Liu S, Han X, Yan Y, Sun B, Chang Y. Quality of life and its influencing factors in patients with post-traumatic epilepsy. *Chin J Traumatol* 2011;14(2):100-103.
- [15]. Mrabet H, Mrabet A, Zouari B, Ghachem R. Health-related quality of life of people with epilepsy compared with a general reference population: A Tunisian study. *Epilepsia* 2004;45(7):838-843.
- [16]. Melikyan E, Guekht A, Milchakova L, Lebedeva A, Bondareva I, Gusev E. Health-related quality of life in Russian adults with epilepsy: The effect of socio-demographic and clinical factors. *Epilepsy Behav* 2012;25(4):670-675.
- [17]. Pauli C, Thais MEO, Claudino LS, Bicalho MAH, Bastos AC, Guarnieri R, Nunes JC, Lin K, Linhares MN, Walz R. *Epilepsy Behav* 2012;25:208-213.
- [18]. Zhao Y, Wu H, Li J, Dong Y, Liang J, Zhu J, Chen B, Li J. Quality of life and related factors in adult patients with epilepsy in China. *Epilepsy Behav* 2011;22:376-379.
- [19]. Bautista RED, Glen ET. Seizure severity is associated with quality of life independent of seizure frequency. *Epilepsy Behav* 2009;16:325-329.

- [20]. Elsharkawy AE, Thorbecke R, Ebner A, May TW. Determinants of quality of life in patients with refractory epilepsy who were eligible for surgery or who rejected surgery. *Epilepsy Behav* 2012;24:249-255.
- [21]. Guekht AB, Mitrokhina TV, Lebedeva AV, Dzugaeva FK, Milchakova LE, Lokshina OB, Feygina AA, Gusev EI. Factors influencing on quality of life in people with epilepsy. *Seizure* 2007;16:128-133.
- [22]. Liou H, Chen R, Chen C, Chui M, Chang Y, Wang J. Health related quality of life in adult patients with epilepsy compared with a general reference population in Taiwan. *Epilepsy Res* 2005;64:151-159.
- [23]. Van Hout B, Gagnon D, Souetre E, Ried S, Remy C, Baker GA, Genton P, Vespignani S, McNulty P. Relationship between seizure frequency and costs and quality of life of outpatients with partial epilepsy in France, Germany and the United Kingdom. *Epilepsia* 1997;38(11):1221-1226.
- [24]. Harden CL, Maroof DA, Nikolov B, Fowler K, Sperling M, Liporace J, Pennell P, Labar D, Herzog A. The effect of seizure severity on quality of life in epilepsy. *Epilepsy Behav* 2007;11:208-211.
- [25]. Smith G, Ferguson PL, Saunders LL, Wagner JL, Wannamaker BB, Selassie AW. Psychosocial factors associated with stigma in adults with epilepsy. *Epilepsy Behav* 2009;16(3):484-490.
- [26]. Kanner AM, Schacter SC, Barry JJ, Hersdorffer DC, Mula M, Trimble M, Hermann B, Ettinger AE, Dunn D, Caplan R, Ryvlin P, Gilliam F. Depression and epilepsy: Epidemiologic and neurobiologic perspectives that may explain their high comorbid occurrence. *Epilepsy Behav* 2012;24:156-168.
- [27]. Mosaku KS, Fotoye FO, Komolafe M, Lawal M, Ola BA. Quality of life and associated factors among adults with epilepsy in Nigeria. *Int J Psychiat Med* 2006;36(4):469-481.
- [28]. Tracey JI, Dechant V, Sperling MR, Cho R, Glosser D. The association of mood with quality of life ratings in epilepsy. *Neurology* 2007;68(14):1101-1107.
- [29]. Meldolesi GN, Picardi A, Quarato PP, Grammaldo LG, Esposito V, Mascia A, Sparano A, Morosini P, Di Gennaro G. Factors associated with generic and disease-specific quality of life in temporal lobe epilepsy. *Epilepsy Res* 2006;69:135-146.

- [30]. Dias R, Bateman LM, Farias ST, Li C, Lin T, Jorgensen J, Seyal M. Depression in epilepsy is associated with lack of seizure control. *Epilepsy Behav* 2010;19:445-447.
- [31]. Sancho J, Ivanez V, Molins A, Gomez VL, Masramon X, Perez M. Changes in seizure severity and quality of life in patients with refractory partial epilepsy. *Epilepsy Behav* 2010;19:409-413.
- [32]. Kwon O, Park S. What is the role of depressive symptoms among other predictors of quality of life in people with well-controlled epilepsy on monotherapy? *Epilepsy Behav* 2011;20:528-532.
- [33]. Selai CE, Trimble MR. Quality of life assessment in epilepsy: the state of the art. *J Epilepsy* 1995;8:332-337.
- [34]. Stainton-Rogers W. *Critical Approaches to Health Psychology*. In: Marks DF, editor. *The Health Psychology Reader*, London: Sage; 2002, p. 286-303.
- [35]. Rosenberg R. Health-related quality of life. Between naturalism and hermeneutics. *Soc Sci Med* 1995;41(10):1411-1415.
- [36]. Larkin M, Watts S, Clifton E. Giving voice and making sense in interpretative phenomenological analysis. *Qual Res Psychol* 2006;3:102-120.
- [37]. Smith JA, Flowers P, Osborn M. Interpretative phenomenological analysis and the psychology of health and illness. In: Yardley L, editor. *Material Discourses of Health and Illness*, London: Routledge; 1997, p 68-91.
- [38]. Kugelmann R. Health in the Light of a Critical Health Psychology. *Psicol Caribe* 2003;11:75-93.
- [39]. Hermann B, Jacoby A. The psychosocial impact of epilepsy in adults. *Epilepsy Behav* 2009;15:S11-S16.
- [40]. Rapport F, Clement C, Doel MA, Hutchings HA. Qualitative research and its methods in epilepsy: Contributing to an understanding of patients' lived experiences of the disease. *Epilepsy Behav* 2015;45:94-100.
- [41]. Kerr C, Nixon A, Angalakuditi M. The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. *Seizure* 2011;20:764-774.
- [42]. Admi H, Shaham B. Living with epilepsy: Ordinary people coping with extraordinary situations. *Qualitative Health Research* 2007;17:1178-1187.
- [43]. Raty LKA, Wilde Larsson BM. Patients' perceptions of living with epilepsy: A phenomenographic study. *J Clin Nurs* 2011;20:1993-2002.

- [44]. Schneider JW, Conrad P. Medical and sociological typologies: The case of epilepsy. *Soc Sci Med* 1981;15(A):211-219.
- [45]. Nijhof G. Heterogeneity in the interpretation of epilepsy. *Qual Health Res* 1998;8(1):95-105.
- [46]. Faircloth CA. Epilepsies, identities, and difference: Horizons of meaning for individuals with and epilepsy. *Qual Health Res* 1998;8(5):602-617.
- [47]. Faircloth CA. Revisiting thematisation in the narrative study of epilepsy. *Sociol Health Ill* 1999;21(2):209-227.
- [48]. Jacoby A, Ring A, Whitehead M, Marson A, Baker GA. Exploring loss and replacement of loss for understanding the impacts of epilepsy onset: A qualitative investigation. *Epilepsy Behav* 2014;33:59-68.
- [49]. Collard SS, Marlow C. The psychosocial impact of exercising with epilepsy: A narrative analysis. *Epilepsy Behav* 2016;61:199-205.
- [50]. Crossley ML. *Rethinking Health Psychology*. Buckingham: Open University Press; 2000.
- [51]. Nettleton S. *The Sociology of Health and Illness*. Cambridge: Polity Press; 1995.
- [52]. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis. Theory, Method and Research*. London: Sage; 2009.
- [53]. Smith JA, Osborn M. *Interpretative Phenomenological Analysis*. In: Smith JA, editor. *Qualitative Psychology. A Practical Guide to Research Methods*. 2nd ed. London: Sage; 2008, p 51-81.
- [54]. Finlay L. *Debating Phenomenological Research Methods*. *Phenomenol Prac* 2009;3(1):6-25.
- [55]. Yardley L. *Material Discourses of Health and Illness*. London: Routledge, 1997.
- [56]. Marks DF, Murray M, Evans B, Willig C, Woodall C, Sykes CM. *Health Psychology. Theory, Research and Practice*. London: Sage, 2005.
- [57]. Scambler G. Patient perceptions of epilepsy and of doctors who manage Epilepsy. *Seizure* 1994;3:287-293.
- [58]. Chamberlain K. Do you really need a methodology? *QMIP Bulletin* 2012;13(spring):59-63.
- [59]. Taylor CM. *Interviewing*. In: Holloway I, editor. *Qualitative Research in Health Care*, Berkshire: McGraw-Hill; 2005, p.39-55.
- [60]. Yardley L. Dilemmas in qualitative health research. *Psychol Health* 2000;15:215-228.

- [61]. Van Elst LT, Baker G, Kerr M. The psychosocial impact of epilepsy in older people. *Epilepsy Behav* 2009;15:S17-S19.
- [62]. Kilinc S, Campbell C. The experience of discontinuing antiepileptic drug treatment: An exploratory investigation. *Seizure* 2008;17(6):505-513.
- [63]. Flick U. *An Introduction to Qualitative Research*. London: Sage, 1998.
- [64]. Miller J, Glasner B. The “inside” and the “outside”. Finding realities in interviews. In: Silverman D, editor. *Qualitative Research. Theory, Method and Practice*, London: Sage; 2004, p.123-139.
- [65]. Gray DE. *Doing Research in the Real World*. London: Sage; 2009.
- [66]. Moustakas, C. (1994). *Phenomenological Research Methods*. London: Sage.
- [67]. Chamberlain K. Qualitative research, reflexivity and context. In: M Murray, editor. *Critical Health Psychology*, Basingstoke: Palgrave; 2004, p121-136.
- [68]. National Institute for Health and Care Excellence. *The epilepsies: the diagnosis and management of the epilepsies in adults and children in primary and secondary care*. Author: London, 2012.
- [69]. Bury M. Chronic illness as biographical disruption. *Sociol Health Ill* 1982;4(2):167-182.
- [70]. Thorne S, Paterson B, Acom S, Canam C, Joachim G, Jillings C. Chronic illness experience: Insights from a metastudy. *Qual Health Res* 2002;12(4):437-452.
- [71]. Bendelow G. *Health, Emotion and the Body*. Cambridge: Polity Press, 2009.