

Proposal of an Integrative Model of Adjustment to Chronic Conditions (IMACC): An understanding of the process of psychosocial adjustment to living with type 2 diabetes

Abstract

Psychosocial adjustment to living with a chronic condition was explored in this grounded theory study, focusing on type 2 diabetes. In spite of a range of relevant theories there is limited understanding of the process of adjustment. The study aimed to address this issue. That was achieved through collecting and analysing personal narratives using individual interviews and focus groups. This allowed for the development of a normative Integrative Model of Adjustment to Chronic Conditions (IMACC) based on biopsychosocial principles. The IMACC has the potential to lead to improved understanding of adjustment processes.

Keywords

psychosocial adjustment, chronic conditions, diabetes type 2, biopsychosocial model, grounded theory

Introduction

It is estimated that around 15 million people in England live with a chronic medical condition (Department of Health, 2015). A diagnosis usually requires individuals to change lifestyle, ranging from minor changes to significant life alterations. Successful adaptation of lifestyle, or good psychosocial adjustment, is important for optimal management of a chronic condition, but also for adequate physical and emotional functioning and quality of life (De Ridder, Geenen, Kuijer & Van Middendorp, 2008). There is a range of relevant psychological theories, however, few, if any, synthesise what seems to be a complex psychological process. This study explored the experience of adjustment for people with type 2 diabetes with the aim of developing a deeper understanding of the process of psychosocial adjustment in chronic medical conditions and proposing a more comprehensive theoretical basis for the further development of effective interventions in the care and management of chronic conditions.

Type 2 diabetes is a chronic condition, which causes increased blood sugar levels. This can have serious long term consequences if not managed appropriately (NHS Choices, 2016). Recent years have seen a dramatic increase; according to Diabetes UK (2016a, 2016b) there are around 3.2 million people diagnosed with diabetes in the UK, the majority with type 2 diabetes. They further estimate that over a million people have type 2 diabetes without being aware of it (Diabetes UK, 2016c). Once diagnosed, people need to learn to manage their condition through diet and exercise, with the possible addition of pharmacological treatments (The National Collaborating Centre for Chronic Conditions (NCC-CC), 2008). Some people struggle to adhere, and lack of psychosocial adjustment means a risk of developing later complications (Diabetes.co.uk, 2016; NHS Diabetes, 2015; Falvo, 2009). Coates and Rae (2006) emphasised the importance of research into factors influencing self-management in diabetes, claiming that our understanding of the complexity of lifestyle management and its interaction with pharmacological interventions is limited and that we are not able to effectively help patients achieve the necessary changes for optimal care.

Many factors influence adjustment; people with objectively similar conditions of similar severity may adjust more or less successfully (Smedema, Bakken-Gillen, & Dalton, 2009). Adjustment in chronic conditions has been conceptualised both as a *state* and a *process*. The *state* of adjustment implies optimal physical, cognitive, and emotional functioning achievable within the constraints imposed by the condition in both private, social, and vocational contexts, as well as a good quality of life (Sharpe & Curran, 2006). However, people with chronic conditions negotiate a period of change and adaptation before they reach the best possible level of functioning and some may only adjust partially, leaving them with significant difficulties of emotional and/or functional nature. Adjustment is therefore often considered a *process* of adaptation. The complexity of this process is illustrated by a range of existing theories and models like the World Health Organization International Classification of Functioning, Disability, and Health (ICF) model (Chan, Gelman, Ditchman, Kim & Chiu, 2009) and various stage models (Smedema et al., 2009).

Theoretical synthesising of factors relevant to psychosocial adjustment is a complex task and several models, like Walker, Jackson and Littlejohn's (2004) model of adjustment to chronic illness, have been suggested. Their model synthesised central theoretical concepts such as appraisal, stress and coping. They used biopsychosocial principles (Gatchel, 2004), which stipulate that vulnerability allows environmental stressors to impact on an individual's disease and physical function. This in turn affects adjustment via psychosocial responses that either modify or exacerbate the effects of the stressor. They further suggested that a biopsychosocial model of chronic illness should include theories such as Monat and Lazarus's (1991) claim that stressors include not only environmental and psychological stressors, but also physiological conditions, acting as stressors, and physiological consequences of psychological responses, e.g. changes in cortisol levels (Chrousos, 2009). In the case of diabetes, a central physiological stressor would presumably be blood glucose levels, which can cause stressful physical symptoms if these are outside the normal range (NHS Choices, 2016).

Sharpe and Curran (2006) suggested a stage model focusing on the role of illness beliefs. However, they acknowledged that this model applies to individuals without psychological disorders. So the illness belief focus is not adequate for an explanatory model of adjustment for a large part of the population. Both models above were developed through synthesis of existing theories, but neither offer an understanding of the underlying psychological processes that help or hinder people moving through the process of adjustment over time. Neither do they illustrate how people deal with moments of heightened stress.

Prochaska (2008) demonstrated the usefulness of the trans-theoretical model of behaviour change for a range of conditions, which require behavioural change in order to comply with disease management. This model offers insight into the psychological processes of change, however, it offers limited understanding of how these processes are influenced by the individual's pre-morbid personality or indeed their current social and environmental context.

Rather than using theoretical synthesis the purpose of this study was to explore the experience of adjustment to type 2 diabetes through qualitative analysis of participants' narratives. The analysis aimed to conceptualise emergent themes and, if supported by the data, to link these with theoretical concepts from cognitive behavioural theory (CBT) (Twohig, Woidneck & Crosby, 2013), an established theory relevant to psychological processes. The primary aim was to develop and propose a conceptual frame and a model of adjustment to chronic conditions in general, and to type 2 diabetes in particular.

Assuming that adjustment is a normal psychological process, the aim for a potential model was to conceptualise it as a normative model.

Method

Ethics and participants

Ethical approval for this study was obtained through a University Research Ethics Committee. Eligibility criteria were: 1) A diagnosis of type 2 Diabetes Mellitus, 2) between one to five years post-diagnosis, and 3) capacity to recall and reflect on personal experiences in relation to this diagnosis and subsequent life changes. A short recruitment interview assured eligibility prior to participation, recall was determined by asking participants to briefly talk about the time of diagnosis. Consequently, twelve people were excluded.

Sampling was based on the assumption that the process of adjustment is a normal human process, similar regardless of gender, age, or the type of adaptation needed. Hence, eleven participants were purposively selected using maximum variation sampling. One participant withdrew, leaving ten participants; eight women, two men, age range 46 to 63. Participants were recruited through various non-NHS contexts to avoid conflicting interests when discussing aspects of care and support. Two participants had lived with diabetes for one year or more, two for two years or more, two for three years or more and four for four years or more. Three participants managed their diabetes with diet alone, five used diet and oral glucose regulating medication, and two used a combination of diet, oral medication and insulin.

Procedure

Informed consent was obtained from each participant. Data collection and analysis were conducted according to Grounded Theory (Glaser & Strauss, 1967) in three phases with two collection events in each phase, and iterative development of interview schedules between phases.

Data were collected through individual interviews and focus groups. This was to access both in-depth material and a broad range of discourse. Four participants were interviewed and six joined two focus groups of each three participants. The first phase involved two interviews with the aim of familiarisation to the area

and development of an initial coding structure. The following two data collection phases both employed one interview and one focus group, providing social comparison (Lewis & Nicholls, 2014) while focusing on the more specific, in-depth questions.

The initial interview schedule used open questions aiming to elicit coherent narratives of change and adjustment. Subsequent schedules emerged by reviewing data to identify areas where more information was needed to further develop the theory, resulting in more specific and focused questions (Charmaz, 2006). Cognitive-behavioural concepts were considered during the development of questions in order to ensure collection of relevant data. Questions aimed to elicit information about beliefs on diabetes, attitudes to lifestyle changes, thoughts about the future, personal values, physical and emotional experiences, adjustment relevant behaviour, and social/interpersonal issues, including experiences of interactions with health professionals.

Analysis

Interviews and focus groups were audio-recorded and transcribed verbatim. The resulting data sets were analysed iteratively following each data collection phase, allowing for development of interview schedules and member checking as the research progressed (Glaser & Strauss, 1967; Willig, 2001).

The data were analysed (Glaser & Strauss, 1967) using open coding and axial coding. The use of *a priori* theoretical concepts from CBT (Westbrook, 2014) in the coding process added to the depth of analysis and supported a more coherent and integrated process modelling of the emerging themes. The theoretical concepts used in the analysis were; schema, rules/assumptions, triggers, cognitions, emotions, sensations and behaviour. Data saturation was reached for normative adjustment in non-insulin dependent type 2 diabetes in phase 3 with no significant additional new information emerging from that group of participants.

Thick descriptions (Lewis & Russell, 2012) were used to support interpretation of the data and development of the model. This allowed generation of a

coherent theoretical framework aiming to describe and explain the process of adjustment to chronic illness.

Trustworthiness

Credibility was assured through use of member validation (Mays & Pope, 2000) and negative case analysis (Pidgeon & Henwood, 1997), achieved through comparison of data from participants with varying levels of adjustment.

Dependability (Lincoln & Guba, 1985) was optimised by keeping a journal of activities and thinking processes throughout the research. Confirmability was assured by basing theoretical developments on the content of the data.

Transferability of the results could potentially be quite broad and allow the results to be used in further research.

Results

The proposed grounded theoretical model (Fig. 1) is conceptualised as an Integrative Model of Adjustment to Chronic Conditions (IMACC). The model, which is based on biopsychosocial principles, is characterised by three levels; pre-morbid personality, ongoing adjustment cycle and maintenance cycle, each containing a sub-model. The interactions between the levels and sub-models are indicated with arrows. The primary aim was to develop a normative model and the data presented refer to normative, functional adjustment.

[Insert Fig. 1]

Pre-morbid personality

Schema. Participants revealed both cognitive and procedural schema material, showing that pre-diagnosis personality, beliefs and habitual behaviours play an important role in adjustment.

Four different schema types were evident in the data. The *Health* schema type reflected health beliefs;

[...] to keep relatively fit and to eat relatively healthily was always important..... (P8)

The *Self* schema type reflected personal identity, self-awareness, self-confidence, ability, and positive attitude;

....if I'm comfortable and I'm well prepared I'm confident in what I'm doing. (P6)

The *Procedural* schema type could be described as automatic habits embedded in the body, e.g. eating and exercise habits;

I would have found it very, very hard if I wasn't [...], I'm not a great sports woman, but I enjoy sport... (P4)

Finally, the *Interpersonal* schema type reflected support from attachment figures;

...my husband was very supportive, [...] I had great support from [...] my children and of course my mum.... (P8)

All relevant schemas are assumed likely to interact with each other and together form the pre-morbid personality with core beliefs.

Rules. The data relevant to schemas were also significant to rules and assumptions. According to cognitive theory these are assumed to be tacit expressions of a person's schemata (Mulhern, 2010), such as habitual behaviours and responses based on core beliefs, and as such forming the same structure as described above.

Critical incident – diagnosis. The time of diagnosis was found to be the critical incident initiating the process of adjustment. Facilitating aspects included preparedness through family history and/or experience of symptoms;

As I've said, it wasn't a surprise, because I know so many people, who have it, knew it was in the family. (P2)

I think part of the reason I wasn't entirely surprised was [...] when I was an adolescent, I used to [...] shake with hunger. (P3)

Ongoing adjustment cycle

The period of adjustment following diagnosis was conceptualised as an ongoing cycle involving five areas of adjustment (listed below). These areas of adjustment did not appear to be discrete, subsequent phases, but rather aspects of adjustment, of which all or most seemed to be present to a greater or lesser degree during the whole period of adaptation and change.

Taking Stock. This area is characterised by initial reactions and evaluation of lifestyle;

...what happened [...] was this business of [...] getting in there and finding out OK so you've got it, so what does that mean? What can you do about it? (P2)

However, the *Taking Stock* area is not only an initial phase, it is reactivated by the prospect of facing new challenges in later stages of adjustment;

.... the doctor said: "You cannot continue like this, you're having to starve yourself to get to [...] the 6.5, so I then had to go on insulin, ... (P9)

Learning New. The majority of data related to the second area of adjustment, which was conceptualised as consisting of three major parts; *Knowledge, Skills* and *Attitudes*:

Knowledge about e.g. diet and exercise;

I had already read loads of books [...], so I knew the right foods to eat. [...] I knew what to do, I wasn't particularly doing it, but I knew what I was supposed to do. (P7)

Skills in managing weight, diet, exercise and glucose levels;

...since I was diagnosed I actually cook more [...] I make soups, [...] obviously no salt in them... (P8)

...someone gave me an exercise bike and I really got into that. (P5)

Attitudes played a significant role and the data covered a range of areas including taking personal responsibility, engaging with change, showing restraint, but also being tolerant with oneself;

...people aren't deprived by having diabetes [...] there's no reason, if you take your medication and you look after yourself..... (P4)

I don't want it to COMPLETELY control my life to a point where I can't go out and enjoy myself now and again. (P5)

Support. The area of *Support* had several aspects, including access to good health care and education;

...Diabetic Nurse, who was brilliant, [...] really sort of running the race with me if you like.... (P8)

...going to the DESMOND [...] you understood things like the different kinds of fat... (P7)

It was important to be able to communicate needs to the family and wider social context, and to have contact with others with diabetes;

I do have support from family and friends... (P7)

I'm going to join [...] my local diabetes group... (P3)

The environmental context could also be a source of support:

I enjoy the walking much more [...] I [...] just felt so good when I had achieved it... (P7)

Letting Go. This area included strategies to avoid temptations, changed shopping and eating habits and cognitive strategies involving flexibility, self-praise and self-motivational thinking, but also a sense of loss;

... you've got to make sure that [...] in the fridge, there's something there that you can eat. (P7)

I suppose it was like the stages of grief [...] pining to be back where I had been, without this..... (P8)

Accept and Integrate. Participants, who gave the impression of being well adjusted, were able to appreciate a better lifestyle and feeling more fit and healthy;

I have a much healthier life style now....., which is a good thing.... (P5)

Previous experience of serious illness and adjustment facilitated acceptance.

...it [rheumatoid arthritis] was much worse for me, it stopped me doing an awful lot of things [...] what has the diabetes affected? Pffff – I can't sit and eat a whole bar of Galaxy chocolate – it's not the end of the world. (P6)

Maintenance cycle

The third level of the model, the maintenance cycle, is similar to the theoretical cognitive-behavioural maintenance cycle for depression (Mulhern, 2010) with negative cognitions, emotions and sensations interacting to shape safety behaviours, which maintain rather than resolve the issues faced. The data supported use of the cognitive-behavioural a priori codes and the analysis showed that the psychological processes evident in the data fitted the cognitive-behavioural model well.

Challenging situations triggering the maintenance cycle included both external and internal (physiological) stressors;

....it's a kind of overall body sensation [*hypo-glycaemia*], where you do feel clammy, [...] you can quite easily get upset with people... (P9)

There was also evidence for the emotional, physiological, and behavioural elements of the maintenance cycle, for instance;

...some of the frustration and anger is towards the outside and some of it I do turn in on myself and I can get quite distressed about it at times as well. (P3)

There were however two important differences between the standard maintenance cycle and the cycle proposed in the adjustment model in terms of cognitions. One was the proposal that automatic cognitions triggered by diabetes-related challenging situations are more often than not characterised by a cognitive conflict. The present analysis found that most conflicts centred round the three middle phases of the adjustment cycle; *Learning New* (e.g. learning to cook for oneself), *Support* (e.g. not having a family to cook for), and *Letting Go* (e.g. letting go of the easy meal options);

I can cook and I do cook, but [...] I'm not very good at cooking for myself, so [...] not on my list! (P3)

Another difference is that the model includes an element of resolution. Normal adjustment processes allow for functional resolutions to the cognitive conflicts arising from challenging situations, leading to adaptive behaviour. It also indicates that for well-adjusted individuals, acceptance and integration is not a matter of no longer perceiving the diabetes to be a challenge causing conflicts, rather it is an acquired capacity to negotiate these challenges and find a functional and reasonably satisfactory resolution;

...providing you're doing enough exercise before and after, you can get away with a certain amount [*of sugary food*]... (P5)

Emotional aspects of the conflict were moderated by positive emotions and feelings of wellness (sensations). These were helpful in overcoming typical negative emotions such as frustration or irritation.

The best thing that's come out of diabetes [...] is my taste buds are back. I used to rush my food, now I'm eating slow and [...] I thoroughly enjoyed that... (P10)

Finally, looking at the IMACC as a whole, the data support the proposal that aspects of the pre-morbid personality, when triggered by a critical incident, are funnelled into the ongoing cycle of adjustment. Issues in the pre-morbid personality and/or issues arising during the period of adjustment may form barriers or snags in one or more of the five areas, preventing the person moving forward with their adjustment process. Situations where these snags are encountered will trigger the maintenance cycle. If the cognitive conflict is resolved without causing significant distress the sense of resolution will facilitate and strengthen acceptance and integration (outcome A). If, however, the cognitive conflict is not resolved in a functional way the problems will be maintained (outcome B). In normative adjustment people seem to eventually reach a resolution, which enables them to adjust successfully by changing relevant attitudes and behaviours. It is assumed that such changes demonstrate changes in the schema-level, hence the arrow from the adjustment cycle up to schemas.

Discussion

The use of grounded theory in combination with established CBT concepts allowed for the development and proposal of a model relevant to the psychological processes of adjustment, both over time and in moments of challenge from both internal and external stressors. The data supported integration of biopsychosocial principles and pointed towards psychological theories beyond CBT (see below), hence the suggestion that the model is integrative. Finally, rather than synthesising existing theories it proposes a view of the adjustment process 'from within' the individual.

Participants appeared to be on a continuum of adjustment, which was advantageous for negative case analysis. However, data saturation was not achieved for insulin dependent participants, most likely because they seemed to be at an earlier stage of adjustment. This suggests that a narrow purposive sampling based on levels of adjustment might be useful in further studies verifying the model. Another issue was the low number of male participants. Some research suggests that this can be a concern in mental health research (Woodall, Morgan, Sloan, & Howard, 2010)

The model nevertheless fitted data from all participants. Issues of adjustment were expressed as barriers/snags to progression relevant to one or more areas in the ongoing adjustment cycle. The lack of saturation for less adjusted participants was in the topic of snags. Further research focusing on identification of typical snags would be valuable in view of potential future application of the model as a therapeutic tool.

The use of *a priori* CBT concepts allowed firstly the identification of four distinct schema types, all of which are corroborated in existing literature; Rosenstock's (2000) Health Belief Model is relevant for the *Health* schema type, and *Self* schemas include confidence and resilience (Yi, Vitaliano, Smith, Yi, & Weinger, 2008). *Procedural* schemas are behavioural schemas relevant to physiological habits such as exercise, eating, resting etc., assumed to be the product of predominantly procedural learning (Wilkinson & Jahanshahi, 2015). This study suggests that procedural schemas are central to understanding behaviour change.

Of particular interest is the *Interpersonal* schema type, which links to theories about the role of support in adjustment (Chronister, 2009). The quality of personal relationships (and hence perception of support) is dependent on individual attachment styles (Harding, Beesley, Holcombe, Fisher & Salmon, 2015). Attachment is one of the central interpersonal theories in psychology, and attachment style has been shown to have a significant impact on self-management and outcomes in diabetes (Ciechanowski et al., 2004), for instance, through the impact on the patient-provider relationship (Ciechanowski, Katon, Russo & Walker, 2001). The model proposes that *Interpersonal* schemas are linked to the adjustment area of *Support*, which in turn impacts on the maintenance of conflictual cognitions. The notion of conflict involving significant relationships points towards psychodynamic theories. Boston Change Process Study Group (2007) argued that lived interactions are primary in triggering intrapsychic conflicts. With attachment theory and psychodynamic conflict theory highly relevant to the model, it would be more accurate to describe the model as integrative. Further research into this aspect of the model is needed to understand the nature of interpersonal schemas and the role of

attachment, for instance, an investigation of the impact of close relationships on the process of adjustment.

Another research question is whether the above four schema types are sufficient to explain the influence of the pre-morbid personality on adapting to chronic conditions. Chronister and Johnson (2009) emphasised the role of culture and diversity in adjustment. Not only in terms of ethnicity, but also disability as a distinct sub-culture. It could be argued that cultural aspects reside within *Interpersonal* schemas, but it may be useful to separate out the cultural aspects of personality, in particular relating to the culture of disability, which may impact on a person's ability to adjust optimally.

Furthermore, this study includes relevant biological aspects from the onset of diabetes (*critical incident*), the impact of symptoms (e.g. hypoglycaemic incidents) and the physiological symptoms of distress. However, MacRae et al. (2015) reviewed issues facing people with intellectual disabilities in managing diabetes, so to adhere more comprehensively to biopsychosocial principles the pre-morbid level of the IMACC may need to be modified to reflect what impact pre-existing physical and mental impairments might have on the process of adjustment, in addition to the psychological schemas evidenced here.

This study suggests that pre-morbid personality schemas impact on the process of adjustment (hence the funnel in the model) by either facilitating or creating barriers to adjustment in one or more of the areas of adjustment. Sharpe and Curran (2006) suggested that self-schemas, world schemas and illness specific beliefs are important for adjustment and this study corroborates that, while suggesting further schema-constellations.

However, adjustment is not only dependent on an individual's personality. Of the suggested five areas in the *Ongoing Adjustment Cycle* four are largely intrapersonal. The area *Support* introduces the social and environmental aspects of adjustment. The areas identified are known in the adjustment literature and will not be discussed here. The innovative aspect is the suggestion that adjustment is an ongoing circular process rather than a progression through stages as suggested by, for instance, Sharpe and Curran

(2006). However, it is consistent with the trans-theoretical model of behaviour change (Prochaska, 2008).

The findings in the *Maintenance Cycle* provides an explanatory model of the underlying psychological processes driving, or hindering, the adjustment process. The validity of the standard cognitive-behavioural cycle (Twohig et. al, 2013) is well established and this study found evidence confirming that triggering stressors can be both internal (physiological and/or cognitive) and external. The cognitive-behavioural cycle links well with the research on stress, appraisal and coping in chronic conditions (Walker et al., 2004). Stress is relevant for both *Emotions* and *Sensations*. Coping, whether adaptive or maladaptive, relates to the *Behaviour* aspect, but coping is also conceptualised as a problem solving mechanism and thus relevant to the cognitive aspect of the maintenance cycle, as is appraisals. However, the proposition of a cognitive conflict is unique to this study. The existence of psychological dilemmas and conflicts are part of appraisal and coping; the innovative aspect is the link with areas of the adjustment cycle, in particular the role of the *Support* area. The data suggest that there is an appraisal process considering behaviour change as a threat to a person's relational equilibrium.

The notion of resolution of the cognitive conflict, or the adjustment challenge, is relevant to problem solving theory and practice (Bell & D'Zurilla, 2009). Further research is needed to verify this suggested maintenance cycle specific to adjustment. In addition to investigating the relational aspect of the cognitive conflict, (see above), it could be useful to establish whether there are other constellations of conflicts. The majority of the data in this study pointed towards a conflict between the three areas shown in the model, however, it is likely that other areas are involved. Presumably, motivational issues in *Taking Stock* could be involved in cognitive conflicts.

Conclusion

The proposed IMACC has the potential to provide a framework for further research into adjustment to type 2 diabetes, which in turn may refine the model. This research identified a range of barriers to successful adjustment, however,

more research is needed to understand adjustment difficulties, hence the emphasis on normative, successful adjustment in this article.

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Integrative Model of Adjustment to Chronic Conditions (IMACC)

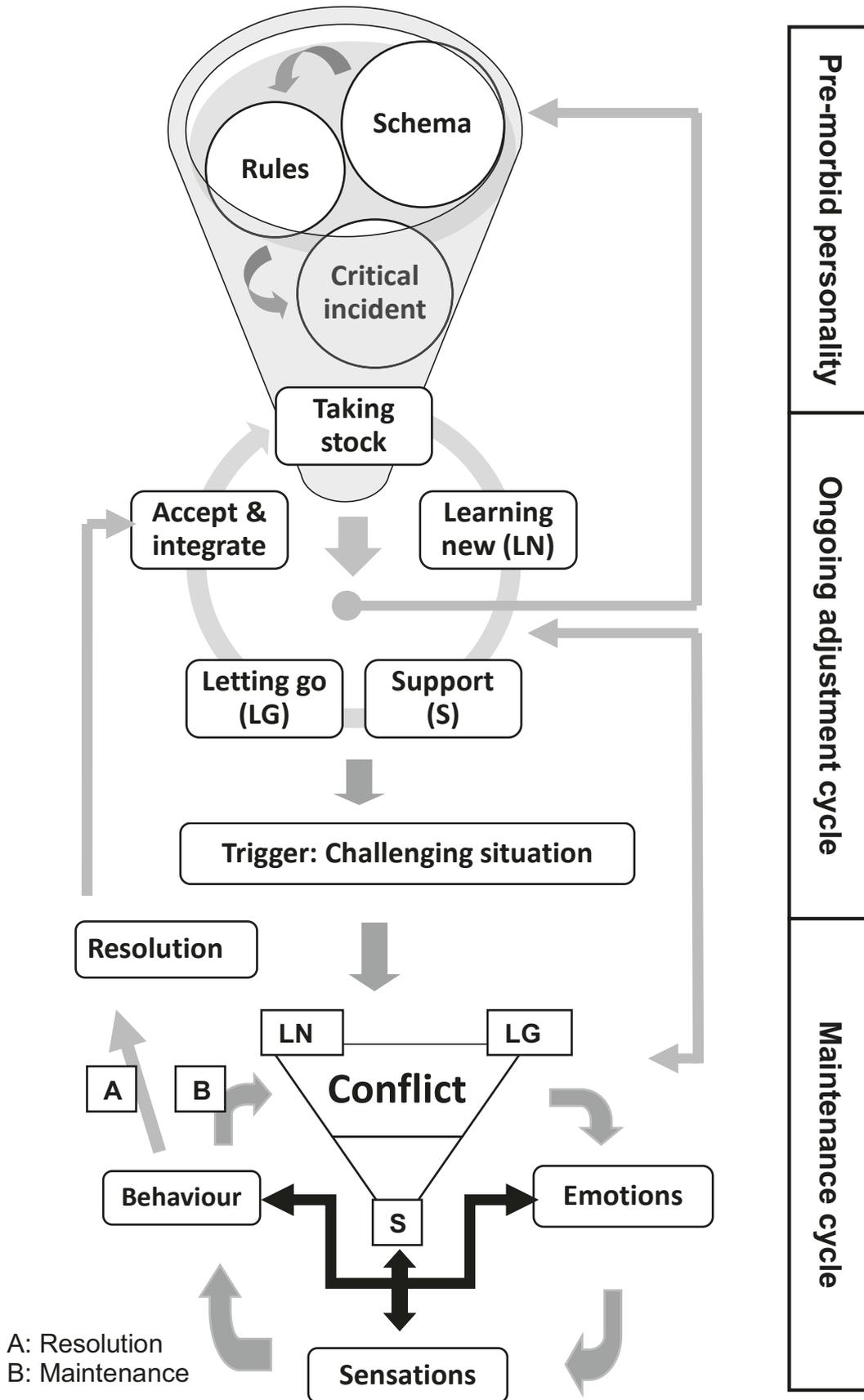


Figure 1: Integrative Model of Adjustment to Chronic Conditions (IMACC)