

Validation of the integrative model of adjustment to chronic conditions: Applicability to adult-onset epilepsy

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Abstract

Adapting to life with adult-onset epilepsy is a challenge and there is a need for better interventions to support people, who have difficulty with psychosocial adjustment to the condition. The integrative model of adjustment to chronic conditions was developed for type 2 diabetes. This study aimed to demonstrate the applicability of the model to adult-onset epilepsy and thus make an original contribution to the development of relevant interventions. Qualitative data from a previous phenomenological study on the experience of adult-onset epilepsy were mapped onto the integrative model of adjustment to chronic conditions using framework analysis. Ten of the original 39 datasets were selected. All 10 datasets were from females diagnosed with epilepsy within 5 years before participation in the original study. The results demonstrated applicability of the integrative model of adjustment to chronic conditions after minor revisions to the model. These findings support further development of the integrative model of adjustment to chronic conditions for use as a clinical intervention for people with adult-onset epilepsy.

Keywords

adult-onset epilepsy, biopsychosocial model, chronic conditions, framework analysis, long-term conditions, psychosocial adjustment

Introduction

The Department of Health (DH) (2012) estimates that around one-quarter of the population lives with a chronic or long-term condition (LTC). An LTC is defined as a condition that cannot currently be cured but must be managed by medication or other treatments or therapies. The DH estimates that care for this section of the population accounts for around 70 per cent of the National Health Service (NHS) expenditure. In a Scottish study, Barnett et al. (2012) found that 42 per cent of the population had one or more LTCs and 23 per cent had multi-morbidity. LTCs increase in prevalence with age; for instance, in the UK, 58 per cent of people older than 60 years live with an LTC and of those, 25 per cent report living with multiple LTCs (DH, 2012). Multi-morbidity has been found to be a particular challenge, with increased healthcare use and issues of coordination of care (Barnett et al., 2012; Rijken et al., 2018). With an ageing population, the need for care is likely to increase significantly, and it is recognised that provision of care

for LTCs is unsustainable, unless self-management approaches are maximised (DH, 2012).

Self-management of an LTC requires lifestyle changes, the extent of which depends on the type and severity of the condition(s) (World Health Organisation (WHO), 2003). Adaptation in order to accommodate the requirements of an LTC is often referred to as psychosocial adjustment. For the purpose of this article, we will refer to that simply as 'adjustment'.

There are two main aspects of adjustment. First, adjustment can be referred to in terms of levels of adjustment, ranging from poor adjustment to good or optimal adjustment, the latter indicating optimal function within the constraints of a condition. This has relevance for the longer

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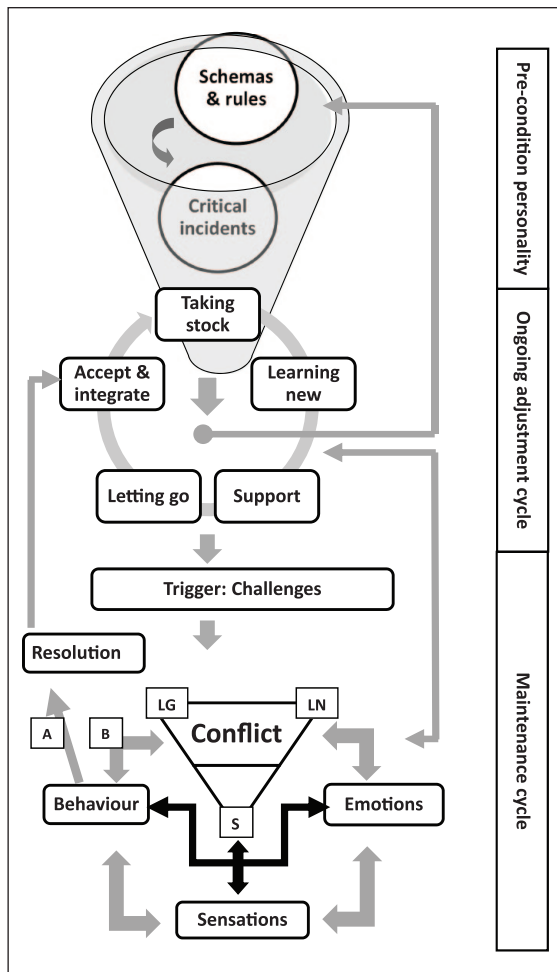


Figure 1. The integrative model of adjustment to chronic conditions – 1st revision (IMACC-R1).

term outcomes for people living with an LTC, in particular for conditions where poor adherence to medical advice will cause a deterioration in the physical condition and potentially life-threatening complications. This in turn has a health economic consequence (WHO, 2003). Adjustment also has implications for people's mental health status; poor adjustment is associated with anxiety, depression and poor quality of life (QOL), which in turn can impact negatively on adjustment. Good adjustment is an important factor for positive mental health and QOL in LTCs (De Ridder et al., 2008; Moss-Morris, 2013).

However, to achieve a good level of adjustment, a period of change and adaptation is required. That implies a process over time, and this second aspect of adjustment is the focus of this article. Moss-Morris (2013) called for a unified model of adjustment to LTCs and offered a working model including a range of factors and how they relate to each other. However, the model does not offer an understanding of the intrapsychic process of adjustment, such as cognitive, emotional and motivational influences on behaviour.

Hammond and Hirst-Winthrop (2018) proposed the integrative model of adjustment to chronic conditions (IMACC), which is a normative model of the process of adjustment based on biopsychosocial principles (Engel, 1982; Fava and Sonino, 2008). It stipulates three core areas (part descriptors) of relevance to adjustment: (1) the impact of pre-condition personality, (2) the ongoing cycle of adjustment after the onset of the condition and (3) the psychological process of either adjusting or maintaining adjustment issues, such as maladaptive behaviours. Each part of the model consists of several components (component descriptors) illustrating the relevant biopsychosocial processes (see Figure 1). The model was developed using grounded theory (Glaser and Strauss, 1967), with a focus on the psychological process of adjustment to type 2 diabetes. In particular, the inclusion of a maintenance cycle using concepts from cognitive-behavioural theory makes the model directly applicable to clinical practice as a tool for assessment and intervention.

The IMACC is a biopsychosocial model reflecting the intrapersonal and dynamic process of adaptation. The interaction with the social/environmental dimension is reflected in the component 'Support' (part of the ongoing adjustment cycle). Pre-condition personality factors (e.g. beliefs and habits) relevant for adjustment feed into the ongoing adjustment cycle, where they act as either facilitators or barriers to adjustment. Barriers stemming from either the adjustment cycle or the condition itself form triggers for the maintenance cycle, which is characterised by a cognitive conflict that needs to be resolved in order to change maintenance behaviours. Once resolved, this constitutes an adaptive change in thinking and/or behaviours, which then feeds into the acceptance and integration area of the ongoing adjustment cycle. Once change is consolidated, it is reflected in changes to beliefs and habits, which in turn feeds into identity changes experienced by people living with chronic conditions. If conflicts are not resolved, but rather maintained over longer time, the identity changes are typically of a negative nature.

The IMACC has the potential to be applied in other LTCs, and this article aims to examine the model's applicability to adult-onset epilepsy (AOE). Epilepsy is one of the most common long-term neurological conditions (LTNCs) in the UK, affecting an estimated 602,000 people (Joint Epilepsy Council of the UK and Ireland, 2011). It is well established that people with epilepsy experience poorer health-related QOL than people with other LTCs and the general population (Michaelis et al., 2018). Furthermore, research has highlighted the negative psychological impact of an epilepsy diagnosis, such as, depression and anxiety (Xu et al., 2017), indicating that people with epilepsy could benefit from psychological support in adjusting to their condition. By demonstrating the relevance of the IMACC for AOE, this article makes an original contribution towards

the understanding of adjustment to this condition as well as adding to the evidence base for the IMACC's relevance across chronic conditions.

Research examining adjustment to epilepsy centres around adjustment in children (Wagner and Smith, 2006), including their parents (Carlson and Miller, 2017) and siblings (Kroner et al., 2018), as well as post-surgical adjustment (Elliott et al., 2008). In contrast to this, the impact of AOE has received little research attention, and there is a dearth of evidence examining adjustment to this condition.

A typical issue for people after experiencing their first epileptic seizure is loss of perceived control. Velissaris et al. (2007) explored adjustment trajectories following a first epileptic seizure in 85 adults. They identified a number of strategies used by their participants to regain a perception of control over their condition, including attempting to identify a cause for the onset. Furthermore, a series of positive actions, such as adapting health behaviours and readjusting life and work goals, were evident, as well as more avoidant strategies of viewing the seizure as an isolated event.

Kılınç et al.'s (2017) study of the experiences of people living with AOE found similar themes. The first theme identified was the unpredictability of seizures where concern about a potential seizure was present even in people who had been seizure-free for years. For some, periods of remission would be a relief, whereas others would be concerned, waiting for the next seizure to occur. The second theme was named the ripple effect, where the wider implications of AOE were highlighted, including loss of independence and restrictions on engagement with certain activities. The third and final themes concerned the need to re-evaluate life plans, which for some participants felt like a disruption of their life, for others opened up new opportunities.

With the increased emphasis on self-management for epilepsy (National Institute for Health and Care Excellence, 2012), the importance of supporting the process of adjustment cannot be overstated. However, medical advice is typically focused on treatment choices, use of medication, how to respond to a seizure and restriction of activities, such as driving, cooking hot meals and swimming, that can be dangerous for people with epilepsy (Epilepsy Australia, 2018). There is limited advice on how to adjust to living life with the wider implications of these constraints, as discussed by Kılınç et al. (2017). Epilepsy Action (2018) provides practical advice on, for example, the use of safety aids and equipment and how to safely take part in sport or travelling. Information and advice about well-being, stress and sleep is also provided.

Such advice can be highly valuable to people, who are motivated to change their health behaviour. Barlow et al. (2002) reviewed self-management approaches in LTCs and found that, overall, self-management can be effective in improving physical and psychological health status and QOL. Barker et al. (2018) also found that high levels of engagement with self-management correlates with less use

of healthcare resources. However, access to education is not consistent. According to Laybourne et al. (2015), there are no well-evaluated self-management programmes in the UK to support people with poorly controlled epilepsy. However, such programmes do exist. For instance, in the United States, the Managing Epilepsy Well (MEW) Network is dedicated to developing, testing and delivering self-management programmes and training (Centers for Disease Control and Prevention, 2019).

According to the WHO (2003), only around 50 per cent of people living with an LTC in developed countries adhere to medical advice, and they reported non-adherence in 40–60 per cent of adults with epilepsy. Although Mathes et al. (2012) critiqued the basis for these claims and their suitability for extrapolation to all developed countries, it is consistent with the study of Barker et al. (2018). They investigated levels of engagement in a large cohort and found that only 13 per cent were 'highly activated' in self-management and 46 per cent were active, but with limited confidence and skill. A total of 22 per cent showed little to no engagement and 19 per cent lacked knowledge and confidence for self-management. Patients unlikely to engage were found to be typically older women from deprived areas. Specific to epilepsy, Davis et al. (2008) found 39 per cent non-adherence to medication in adults with epilepsy, causing increased likelihood of hospital admissions and/or need for emergency care. Furthermore, adherence to treatment advice and self-management is not necessarily an indicator of good adjustment. Some people adhere due to anxiety about the consequences of non-adherence or they suffer significant side-effects of their medication, leading to poor QOL (Hovinga et al., 2008).

There are multiple, complex factors impacting adherence and adjustment. The WHO (2003) lists socioeconomic factors, healthcare systems, condition- and treatment-specific factors and patient-related factors. O'Rourke and O'Brien (2017) investigated barriers to adherence in adults with epilepsy and found issues such as specific beliefs about medication, poor mental health, perceived low social support and poor patient–physician relationship. These factors are consistent with the findings in Hammond and Hirst-Winthrop's (2018) IMACC, which supports the aim of investigating the potential for the IMACC's applicability to the area of AOE. To achieve that, this project used framework analysis to map qualitative data from Kılınç et al.'s (2017) study of experiences of people living with AOE onto the IMACC in order to ascertain not only the model's applicability but also any need for revision of the model.

Method

Design

The study employed analysis of secondary data from the Kılınç et al. (2017) study. Framework analysis (Gale et al.,

2013) offers a method for highly structured analysis of qualitative data with the aim of systematically applying codes from an agreed analytical framework onto relevant datasets (for more details please see section ‘Procedure and analysis’ below). This made it suitable for mapping the aforementioned data onto the model components of the IMACC (Hammond and Hirst-Winthrop, 2018).

Ethics and dataset

Research ethics approval to conduct secondary analysis on the data was granted by a local university ethics committee. The original study was conducted by the third author (S.K.) and adopted a phenomenological approach to explore the experience of living with AOE. Participants were recruited via advertisements on the Epilepsy Action website and newsletter and a support group in the north-east of England. People with epilepsy were eligible to take part if they had been diagnosed with epilepsy between the ages of 18 and 59 years and were taking anti-epileptic medication. In total, 39 participants took part in the original study, 24 of whom agreed to a follow-up interview 6 months after the first round of interviews. The first interview explored their experience of epilepsy from pre-diagnosis to post-diagnosis, while the second interview focused on specific topics, such as restrictions on daily living and stigma, raised in the first round of interviews (see Kılınc et al. (2017) for a full description of the original study). From the above dataset, the 10 most recently diagnosed participants, who reported that their seizures were uncontrolled, were chosen as the dataset for the current study.

The selected participants in the current study were all female and aged between 20 and 50 years, having been diagnosed with epilepsy 1–5 years previously; six had idiopathic and four had symptomatic epilepsy. Apart from gender and duration of epilepsy, the demographics were comparable to the original sample of 39 participants. Seven participants took part in a second interview as part of the original study. Therefore, the final dataset comprised 17 interviews.

Procedure and analysis

An independent researcher (second author, A.P.F.; referred to as the analyst) was trained in the use of framework analysis and carried out the data analysis according to Gale et al.’s (2013) recommendations for use of framework analysis in health research.

As secondary data were used for the analysis, transcription of interviews had taken place previously. The analyst familiarised himself with the interview data by reading all transcripts several times, clarifying any ambiguous or unclear areas by asking the original interviewer S.K. (third author). This corresponds to Stages 1 and 2 of the framework analysis (Gale et al., 2013).

In Stage 3, analysis and coding was conducted using NVivo 10. Coding was done using a deductive approach, so no initial free coding was done. Pre-selected codes consisted of all IMACC model components, including sub-components (e.g. the four schema types found under the original component ‘Schema’). The IMACC as a whole, thus, formed the analytical framework, based on the three main parts of the model (part descriptors) as well as individual components and their sub-components (component descriptors). Each of these was used as the predefined codes (Gale et al., 2013).

To ensure that all framework codes were clearly defined, the first author (L.D.H.) developed clear specifications of all components and sub-components based on the original data from the Hammond and Hirst-Winthrop (2018) study. These were used to ensure that the analyst could clearly distinguish between data matching the specifications and deviating data that would require new open coding. Stage 4 of the framework method (developing an analytical framework) is not applicable for deductive analysis, where the analysis is based on a pre-existing theoretical framework. The analysis, therefore, progressed directly to Stage 5, application of the analytical framework; indexing is the systematic application of codes from the pre-defined analytical framework onto the dataset (Gale et al., 2013). This was done using a constant comparative method with a particular focus on identifying any new material that might prompt additional codes or framework components.

Once all transcripts had been coded, triangulation (Smith and McGannon, 2018) was conducted by all authors by looking at the coding for each transcript as well as the data content of a sample of codes. In Stage 6, the data for each framework component (or code) were summarised and a final matrix was generated. The summaries aimed to capture the range of topics relevant to each code, while ensuring that original meanings were reflected (Gale et al., 2013). This provided an overview of how the dataset mapped onto the framework, including any new codes. The contents of all pre-defined and new codes were examined carefully to determine any need for revision of the IMACC.

Member checking (Taylor, 2005) of the results was not relevant, as the study employed secondary data. However, some member checking had taken place in the original Kılınc et al. (2017) study. All researchers kept a reflexive diary (Chamberlain, 2004), and a clear audit trail of the analysis was ensured.

Results

Overall, the results showed that the data from the Kılınc et al. (2017) study mapped onto all components of the IMACC, and all data showed a fit with the pre-existing structure of the model. Data that added new material were relevant to existing codes and informed minor revisions of

content and/or subdivision of four model components: ‘Schema’, ‘Rules’ (components merged, see section ‘Schema – revision; merger with Rules’), ‘Critical Incident’ (changed to plural, see section ‘Critical Incident – revision to plural: Critical Incidents’) and ‘Trigger; Challenging Situation’ (changed to ‘Challenges’ to accommodate both situation- and condition-specific aspects, see section ‘Trigger: Challenging Situations – revision; change to Challenges’). The revised model is depicted in Figure 1, and details are presented in the following sections.

The following results focus on areas of relevance to AOE that add novel aspects to the IMACC. Where a component is only briefly mentioned, it indicates that findings are similar to what was found in the original study. Such similarities indicate aspects that are not condition-specific and, thus, potentially relevant to a range of LTCs. We refer to the original IMACC article (Hammond and Hirst-Winthrop, 2018) for more details on shared aspects. Each of the following headings refers to either a part descriptor (e.g. ‘Pre-Condition Personality’) or a component descriptor (e.g. ‘Schema – revision; merger with Rules’) of the IMACC.

Pre-Condition Personality

In the original IMACC, this level was referred to as ‘Pre-Morbid Personality’. For purposes of potential clinical use, we suggest a revision to the term ‘Pre-Condition Personality’.

In the Kılınç et al. (2017) study, there were limited data on developmental experiences and beliefs, as participants chose to stay mainly in the here and now in their accounts. Nevertheless, there were some findings relevant to this component.

Schema – revision; merger with Rules. The first model component, Schema, was originally found to consist of four subcomponents (Hammond and Hirst-Winthrop, 2018). The present analysis confirmed this and did not suggest any further subcomponents.

As in the original IMACC study, the data relevant to Schema were also relevant to Rules. The two component concepts stem from cognitive behavioural theory, which assumes rules to be the tacit expressions of schemas (Mulhern, 2010). However, as the data relevant to Schema and Rules are generally a mix of expressed core beliefs and description of habits/activities, we suggest a minor revision: The merger of Schemas and Rules into one component.

Health Beliefs. Prior experience and stereotypical representations of epilepsy were found to be important for reactions to onset and diagnosis. More general health beliefs, like attitudes to medication, also impacted adjustment:

Oh, I had a good understanding of epilepsy to be honest, because I’m a qualified nurse, [. . .]. So I personally don’t have a fear factor over epilepsy. (Rachel, Int2; Encephalitis)

I always thought ‘poor people with epilepsy’, you know, I didn’t understand what it was like until it happened to me. (Kirsty, Int2; Idiopathic)

I don’t even like taking paracetamol for period pain, and I certainly don’t like taking the whack of medication I’m on now. (Rachel, Int1; Encephalitis)

Self Beliefs. The results for this subcomponent were similar to the findings in the original IMACC study. In particular, pre-condition levels of self-confidence, independence and need for control were mentioned as factors relevant to adjustment, as were issues of identity.

Interpersonal Beliefs. Although data relating to pre-condition interpersonal schemas were limited, these were again similar to issues found in the original IMACC study. Participants would refer to themselves as sociable in the past, and some talked about the reaction of their support networks, indirectly indicating access and capacity to use support in varying degrees:

My family’s like really upset about it, and they don’t know why I’ve got it now, and why I didn’t have it as a kid. (Kirsty, Int1; Idiopathic)

Procedural Schema. In the original IMACC study, the term Procedural Schema referred to automatic behaviour like habits that are often embedded in the body. These include diet and exercise, which are relevant not only for LTCs but also for health in general. However, some habits are relevant specifically for adjustment to epilepsy, indicative of things that may change for people after onset of their condition. Examples include driving a car and bathing independently:

Before I was diagnosed? Basically I could drive. (Julie, Int1; Brain tumour)

[Before diagnosis] I could go away and have a bath by myself. (Kirsty, Int1; Idiopathic)

Critical Incident – revision to plural: Critical Incidents. This is the first component where findings from this investigation have prompted a revision. In the original IMACC study, diagnosis was found to be the critical incident, which would start the adjustment process. From the data in this study, we conclude that several different aspects can trigger the adjustment process. We, therefore, suggest a change of the model component to Critical Incidents (plural).

Unsurprisingly, for many participants, the first experience of seizures triggered the adjustment process and, for

some, the time of their life when this happened (for instance, early in their careers) added to the need for adjustment. For others, falls or co-morbidities were the main challenge, while the loss of driving licence and/or employment was the thing that made some participants realise that the condition would change their life:

I was just on the phone to my mam, [. . .] so just as I was talking really, I just kind of like twisted round to the right and that was the last thing I remember. My mam [. . .] came rushing round and I was just like sat there, [. . .]. [. . .]. I didn't know what had happened or anything, so it went from there. (Julie, Int1; Brain tumour)

. . . I fell really badly and broke my leg in two places and er, I thought, well I still don't know what's causing it, and then er, I had another fall and hit my head and ended up in hospital . . . (Kirsty, Int1; Idiopathic)

Ongoing adjustment cycle

This second part of the model consists of five model components, one of which is subdivided into three elements. The modelling of the ongoing adjustment cycle was supported by data from the Kılınç et al. (2017) study, with data from either all or most participants being relevant to each component and element. Where data from some participants were lacking, it was a case of the participants not having discussed the topic, rather than saying anything contradicting the model.

Taking Stock. Taking Stock covers the initial emotional and cognitive reactions, lifestyle assessment and consideration of options. Condition-specific elements of this component include the incapacity to take stock due to the early effects of the condition causing the epilepsy. One participant was able to reach a level of acceptance early, as she saw the epilepsy as the lesser of two evils:

I've [. . .] got on with it and accepted it I think. [. . .]. Well, firstly I was quite glad to find out it was epilepsy and not something worse, [. . .] CJD or something like that, [. . .] at least I'm not going mad. (Lynne, Int1; Idiopathic)

. . . when I came out of the coma I'm sure they'll have said, but because I have such a bad memory erm, I can't really remember. [. . .]. I was in hospital, so er, it didn't really [. . .] mean that much to me then . . . (Rachel, Int1; Encephalitis)

Learning New. As in the original IMACC study (Hammond and Hirst-Winthrop, 2018), three distinct types of learning were found: (1) the need for information and understanding (Knowledge), (2) the need to apply this in practical ways (Skills) and (3) the need to sometimes change old attitudes that might get in the way of optimal adjustment (Attitudes).

Knowledge. Participants expressed a need for knowledge and problems with access to relevant information, including frustration that epilepsy cannot be measured and quantified like some other conditions, causing greater uncertainty. Knowledge about what medication is right for the individual was also central:

I think knowledge is a big help. Even now, you don't get that much information on it. You get the odd pamphlet, that's about it, you don't get a lot of the insight into it. (Rebecca, Int2; Idiopathic)

. . . it can take a long time to find medication to control epilepsy, and, I mean everybody's reactions to it are different . . . (Rachel, Int1; Encephalitis)

Skills. Skills in managing the condition include self-awareness of triggers and re-learning how to live life within the constraints of the condition. This can even lead to discovering new skills and abilities:

The thing is I know what brings them now. Late nights, alcohol, stress. I try to avoid them. (Rebecca, Int2; Idiopathic)

. . . it's left me with the epilepsy [. . .], the only way to do something with that is to challenge it and see how far I can go, [. . .] when I go to the swimming baths for example, I don't even think I could dive beforehand, but I always do dives at the end. (Rachel, Int2; Encephalitis)

Attitudes. Attitudes that may need to change, include pre-condition views on others with epilepsy and not wanting to think about oneself in negative or derogatory terms. Having the ability to see the positive side and internalising the condition can be advantageous to adjustment:

I've also looked after quite a lot of people who've had seizures and I don't like the thought of myself looking, erm . . . looking like the, the memories I've got of other people that I've dealt with. It's quite a degrading position to be in really. (Michelle, Int2; Idiopathic)

. . . getting public transport to work [. . .] meant walking a mile to the station, [. . .] walking another mile at the other end, [. . .] but that was great because I lost a stone in weight (laughs) [. . .], I enjoyed the walk, [. . .], enjoyed not being stuck in traffic, erm, and it's cheaper not having a car . . . (Lynne, Int1; Idiopathic)

Support. The Support component is the extra-personal or social dimension of the IMACC. This includes relations to, for example, family, friends, employers and health professionals, both in terms of perceived and actual support available (or not). It also includes any relevant environmental aspects, for instance, home adaptations and availability of facilities like public transport. A significant amount of the

data related to this component and the area is of crucial importance to the maintenance cycle (see section ‘Maintenance cycle’).

Condition-specific examples of support include issues of stigma and how to deal with that, issues of hiding the illness versus using support, issues of dependency and perceptions and levels of understanding of family:

. . . a big badge saying ‘I have epilepsy’. I mean, I won’t wear that. [. . .] I personally go for the option of, [. . .] medi-tags [. . .] that actually shows the symbol that paramedics would recognise, but Joe Bloggs down the street probably wouldn’t recognise . . . (Rachel, Int1; Encephalitis)

. . . it can be quite difficult [. . .] I think my mum was more upset about it than I was [. . .] she’s always reading things in the newspaper and telling me to go and try acupuncture of some homeopathic remedy . . . (Jane, Int2; Encephalitis)

It’s affected my husband and my children em . . . He [. . .] is quite protective over me . . . If he sees I’m at risk anywhere. It’s hard to accept, but I can appreciate it really. (Michelle, Int2; Idiopathic)

Letting Go. The Letting Go (LG) component concerns coping with losses, not only of previous abilities and identity but also of future potential. The loss of driving licence and employment opportunities is typical in epilepsy. It can also be necessary to let go of old attitudes that are no longer helpful, for instance, resistance to taking medication (see section ‘Health Beliefs’ above):

. . . epilepsy isn’t recognised as a disability, [. . .] nobody wants a 53 year old epileptic person working for them, even if she is the best P.A. I try not to be bitter and twisted but it’s a bit fed up making. (Claire, Int1; Brain haemorrhage)

Acceptance and Integration. Participants were generally aware of the need for acceptance of the condition, but some found it easier than others. A lack of acceptance implies a resistance and a fight ‘against’ the condition, which can cause negative emotions:

No, it has got better, definitely. [. . .] I probably wouldn’t have gone to University if I hadn’t had epilepsy. It’s not all miserable at all. (Sue, Int1; Idiopathic)

You just don’t want that to be a part of you. So, you know, I do get depressed about that side of it. [. . .] I suppose I don’t want to accept that it is a part of me. (Julie, Int1; Brain tumour)

Maintenance cycle

The third part of the IMACC consists of a cognitive behavioural maintenance cycle but with one significant difference. Cognitive behavioural theory stipulates that negative cognitions contribute to the maintenance of maladaptive

thinking and behaviour (Sage et al., 2008). In the original IMACC study, the negative cognitions were consistently found to be characterised by dilemmas or conflicts. That study found cognitions characterised by a conflict, typically between the three components Learning New (LN), Letting Go (LG) and Support (S). The conflict would arise from situations where the condition challenged pre-condition functioning. Maintenance, or perpetuation, of adjustment issues would continue until a resolution to a particular conflict was found and the behavioural response was altered.

In this study, we paid particular attention to the types of conflict in order to investigate whether there might be constellations of conflict other than LN/LG/S, as mentioned above. Two different constellation types were found, see section ‘Cognitive Conflict’. This final section of the results focuses partly on the nature of triggers and partly on these conflict types.

Trigger: Challenging Situations – revision; change to Challenges. Contrary to the original IMACC study (Hammond and Hirst-Winthrop, 2018), we found that not only specific situations would trigger the maintenance cycle. Participants reported that a major challenge was the unpredictable nature of epilepsy, so even when a situation did not present a direct challenge, just the thought of what might happen was perceived as an ongoing challenge. We, therefore, suggest to change this model component to Challenges, with two subcomponents: Challenging Situations and Challenging Aspects of the Condition. The latter includes not only uncertainty about seizures but also actual seizure episodes:

. . . you just don’t know when it’s gonna happen and you get stressed about it because, and then your stress makes your epilepsy worse and, the epilepsy causes the stress, so it’s just a big vicious circle . . . (Kirsty, Int1; Idiopathic)

I have less awareness [. . .], today I couldn’t recognise someone, one of my bosses, and I didn’t realise I was doing it at the time, but actually I realised afterwards that I did that and I didn’t get the option to go back and say sorry. (Sue, Int2; Idiopathic)

Cognitive Conflict. In addition to the type of conflict found in the original study (LN/LG/S), two other types of cognitive conflict were identified, and for both, the Support element was a crucial factor. The first was a lack of motivation for self-management (Taking Stock) and therefore a failure to learn how to deal with the condition (Learning New). In one case, this was caused by an experience of inadequate support from the health professional, who was the initial contact (Support):

It [*epilepsy*] was the last thing I wanted, and I just ignored [. . .] until it got like, I’m at home, the fact that I have got it and I can’t drive, and that things are going to have to change,

like it or not really, and then I realised that I had to take my drugs, I had no choice. [. . .] I'd hate them. Stop them. Take them for a bit [. . .] stop them again. [. . .] no-one really told me I had epilepsy, [. . .] then they were like 'You've got it now, thanks, bye'. 'So what happens now? What do you mean, you can't drive? What's it all about?' [. . .] No-one even told me what kind of epilepsy I had. [. . .] 'Go and see your G.P. and get some carbamazepine', and I was like 'Right, okay, he's not taking it very seriously, I needn't take it very seriously either' (Sue, Int2; Idiopathic)

The second type of cognitive conflict is characterised by the perceived family reactions (Support) as a barrier to changing the way an individual deals with their condition (Learning New). This issue prevents them from letting go (LG) of a potentially unhelpful attitude of independence and secrecy:

. . . it makes my parents more upset because at the moment I'm living with them, [. . .], they're more anxious that something's gonna trigger it off . . . oh . . . it just makes me keep it even more of a secret. It gets on my nerves after a while. It's not about them, I get annoyed 'cos it's not about them. (Sue, Int2; Idiopathic)

Discussion

The aim of this study was to ascertain the applicability of the IMACC to AOE and identify any revisions needed. Data from Kılınc et al.'s (2017) study on the experiences of living with AOE mapped onto all components of the model and did not prompt addition of new components. The data did prompt minor revisions of the model.

The first revision, a merger of the components 'Schema' and 'Rules', was based on the fact that the analysis of the qualitative data does not clearly distinguish between the expressed behaviour (rules) and the underlying beliefs (schemas). Theoretically, it is not a fundamental change of the model; it is merely a simplification.

The second revision, changing the component 'Critical Incident(s)' to plural is more significant. In the original IMACC article (Hammond and Hirst-Winthrop, 2018), that component proposed (based on the data) that testing and diagnosis was the point of triggering the adjustment process. However, as demonstrated in this article, it is more likely that a range of different issues can trigger the need for adjustment, not only the diagnosis. In AOE, the symptomatology is likely to be a key feature triggering the adjustment process. However, for some people, the adjustment process progresses normally until, for example, a comorbidity changes the goal and makes adjustment more challenging. So, this component is relevant not only to incidents starting the process of adjustment but also to incidents that can turn a normally progressing adjustment process into adjustment difficulties and potentially poor adjustment. Szaflarski et al. (2006) found a modest effect of

age of onset on QOL in medication-resistant epilepsy, and they linked this to the practical disruption of an established adult life dependent of, for example, being able to drive. This is consistent with the findings in this study where the loss of independence would lead to adjustment difficulties.

The third revision was change of 'Challenging Situations' to 'Challenges' with two subcomponents 'Challenging Situations' and 'Challenging Aspects of the Condition'. This was prompted by data around the stress of the unpredictability of seizure activity, which is not a 'situation' identifiable at particular time points, rather a challenge that is always present to a varying degree. However, time-specific situations where the condition presented a challenge were also reported, so both aspects are important. This is consistent with other literature identifying the challenge of achieving a good QOL, in spite of practical constraints (situations) and the constant threat of seizures and real or perceived cognitive constraints (aspects of the condition) (Eatock and Baker, 2007; Gois et al., 2011).

The use of secondary data is both a strength and a limitation of this study. This, and the use of data from females only, limits the transferability. However, the fact that data, gathered purely to explore people's experiences of living with AOE, map onto the IMACC and further refine it supports the notion that the IMACC has the potential to be applied to adjustment in LTCs in general. The IMACC aims to model the psychological process of adjustment, regardless of specific conditions. Obviously, more research needs to be done to verify this, both for epilepsy and other chronic conditions. To take the knowledge of adjustment forward, the model needs to be able to incorporate what is already known about adjustment, as well as adding further knowledge. A next step could, therefore, be to review recent literature in this area and compare with other models or theories of adjustment, for instance, Moss-Morris' (2013) factor model of adjustment and Pembroke et al.'s (2017) study of strategies for adjustment. This may allow for further revision of the IMACC to incorporate any missing aspects of adjustment, which are evidenced, but not necessarily expressed by people living with LTCs. However, the significance of what the IMACC offers is an extension of current knowledge by providing an understanding of the process of adjustment over time in a way which is directly applicable to clinical practice. Clinical testing of such application of the model is a priority and should be done in several chronic conditions in order to evidence generalisability. Should the model prove effective in addressing adjustment difficulties in people with LTCs, it could reduce healthcare spending in LTC services, both nationally and internationally. More importantly, it has the potential to improve QOL for people who experience significant difficulties adapting to a life of self-management of their LTC.

Having a generic model of adjustment to chronic conditions could also improve research into adjustment in general and AOE in particular. Previously, research in epilepsy

has relied mostly on QOL and social adjustment measures or lengthy interviews to assess levels of adjustment (Gois et al., 2011; Szaflarski et al., 2006). Whereas these measures are relevant, they have limited scope for identifying and addressing individual barriers to adjustment and may not capture all aspects relevant to adjustment. A model like the IMACC, which theorises the intrapersonal process of adjustment, can form a basis for the development of targeted adjustment measures, systematic research into barriers and coping strategies, as well as providing a tool for clinical intervention.

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