

A patient-centered approach to understanding long-term psychosocial adjustment and meaning-making, 15 to 20 years after epilepsy surgery

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ABSTRACT

Objective: Different psychosocial trajectories have been identified following treatment with epilepsy surgery, as patients adjust to possible changes in seizure frequency and the subsequent impact on their psychosocial functioning. Qualitative research has been key to understanding this adjustment process, particularly in the short-term (2–5 years). Currently, however, there is a lack of qualitative research examining longer-term (>15 years) outcomes, precluding the same rich, detailed understanding of longer-term psychosocial outcomes. Using a grounded theory approach, we explored how patients reflected on and made sense of their adjustment trajectories, 15 to 20 years after surgery. This included the impact of surgery on their sense of self and broader psychosocial functioning.

Methods: We recruited 40 adult patients who had undergone anterior temporal lobectomy (ATL) 15 to 20 years ago (24 females; 26 left-sided). Median age at habitual seizure onset was 9.7 years (Interquartile range; IQR = 13.8), and at surgery was 31 years (IQR = 12). Median length of follow-up was 18.4 years (IQR = 4.3). Comprehensive one-on-one interviews (median time = 86 min, IQR = 28) were used to elicit patient experiences of their surgery and subsequent psychosocial outcomes. Data were analyzed using a grounded theory inductive–deductive process.

Results: Patient narratives revealed a common process of psychosocial change and meaning-making triggered by surgery, which was often perceived as a major turning point in life. Patients reflected on moving through an early postsurgical period (<5 years) of upheaval and psychological disequilibrium. While this period was often remembered as stressful, difficulties were softened and/or reframed in hindsight. Through this process of reframing and meaning-making, patients were able to reestablish equilibrium and a sense of normality. Differences were evident in how patients navigated the process of meaning-making, and the extent to which they felt surgery had changed their self-identity.

Discussion: We propose a model of postsurgical meaning-making, evident in the narratives of patients who have undergone ATL, providing a new perspective on long-term psychosocial outcomes. This model contributes to our understanding of patient well-being and quality of life, by acknowledging the active role that patients play in seeking to create their own sense of normality after epilepsy surgery.

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1. Introduction

Epilepsy surgery is the recommended treatment for patients with drug-resistant focal epilepsy, often resulting in better seizure and quality of life outcomes compared with ongoing treatment with medication [1]. Our current understanding of the impact of surgery on psychosocial functioning primarily spans the presurgical to initial five-year postsurgical period. This research has been invaluable for informing the

short- to medium-term clinical management of patients undergoing this procedure by shedding light on the complex processes of learning to live without epilepsy or facing the uncertainty and disappointment of seizure recurrence [2–7]. For some, successful surgery can result in a paradoxical increase in psychological distress and a process of identity change [3,4,8], and this research has provided clinicians with valuable information for improving early postsurgical psychosocial support [8]. Our understanding of the longer-term psychosocial adjustment process, however, is limited.

Research into long-term (>15 years) psychosocial outcomes of epilepsy surgery generally shows improvements along with improved quality of life, particularly for those who achieve good seizure outcome

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[9–13]. Much of this research, however, focuses on the achievement of specific social milestones, commonly driving, employment, and rates of marriage. Alternatively, research focusing on psychological outcomes has been predominantly restricted to a few studies examining rates of depression and/or anxiety long-term [14–17]. Far less is known about patient perspectives of the outcomes of their surgery, the possible resolution of early adjustment issues, and broader markers of psychosocial functioning. Likewise, no research has examined the active role that patients might play in making sense of their surgical outcomes and its impact on self-identity, despite two long-term studies alluding to the occurrence of ‘identity crises’ after the early follow-up period [17,18].

Qualitative research is key to achieving this deeper level of psychological understanding. Qualitative research provides valuable insights into the experience of living with epilepsy across the lifespan [19–22], and allows researchers to examine the phenomenology of patient experiences and psychosocial processes not captured by statistical methods. To date, however, there are only two qualitative studies of the longer-term psychosocial outcomes of epilepsy surgery [17,23]. One of these, from our research group, focused specifically on patient experiences as they relate to the achievement of social milestones [23], while the other focused on patient expectations and the perceived costs and benefits of surgery [17]. No study to date has explored the psychosocial adjustment trajectories of patients in detail, including any impact on patient self-identity, giving rise to the aim of this study. In particular, we sought to develop a model of the process by which patients adjust to and make sense of their decision to undergo epilepsy surgery and its subsequent impact on their long-term psychosocial functioning.

2. Materials and methods

2.1. Study design

The grounded theory approach of Glaser and Strauss was chosen, because of its benefits for exploring understudied topics and understanding psychosocial processes [19,24–26]. Grounded theory also considers ‘negative cases’ (i.e., those typically considered outliers in quantitative research), thereby capturing the true diversity of patient experiences. This is extremely valuable because patient adjustment trajectories, either in the face of a new illness or following major treatment, are not uniform [27–29]. Individual differences in the ability to adapt are expected and can be lost when focusing on group average data [27].

2.2. Recruitment

This study was conducted as part of a larger project characterizing the long-term psychosocial outcomes of anterior temporal lobectomy (ATL) [23], with the following eligibility criteria: (i) a single ATL for drug-resistant temporal lobe epilepsy (TLE), (ii) age ≥ 18 years at the time of surgery, (iii) intellectual capacity to engage in a lengthy interview process (Full scale IQ; FSIQ ≥ 70), and (iv) a sufficient level of English. All patients were recruited from the Austin Health Comprehensive Epilepsy Program (CEP), where they had undergone presurgical clinical, electroencephalographic (EEG), psychiatric, neuropsychological, and neuroimaging investigations, as well as extensive routine postsurgical medical, neurological, and psychosocial follow-up [30,31]. Routine psychosocial and medical follow-up spanned the initial 24-month postsurgery period; however, some patients received extended regular psychosocial support, with the longest documented clinical follow-up at 7 years.

Recruitment occurred between 2014 and 2016, starting with review of patient records and ending when theoretical saturation was met (Supplementary Fig. 1). One hundred and fourteen patients were identified as having undergone a single ATL between 1994 and 2004 (to ensure a follow-up of ≥ 15 years). Of these, one had died, four were lost to hospital contact, and twenty-seven did not meet study inclusion criteria. Seventy eligible patients were contacted via post in a

consecutive manner, beginning with those who underwent surgery in 1994. Forty-five (60%) agreed to participate. The remaining patients could not be contacted ($n = 18$), declined because of perceived time commitment ($n = 6$), or reported a negative experience of surgery ($n = 1$).

2.3. Participants

Following recruitment, three patients withdrew because of time commitments, one was unable to be scheduled for interview, and another completed the interview but did not return the consent form. Forty patients (57% of those contacted) were therefore interviewed for the current study, representing a robust final sample for qualitative analysis [19,26]. For a grounded theory approach, it is important to intentionally include patients with a range of experiences [32]. This was achieved within our cohort by including patients with different clinical characteristics and postsurgical seizure outcomes, as well as the type of postsurgical psychosocial support received (i.e., face-to-face or over the phone, depending on whether patients lived locally, interstate, or overseas).

Patient demographics are displayed in Table 1. Patients predominantly came from Victoria, Australia (46%), with slightly more females (61%) and left-sided resections (66%). The median age at surgery was 31 years (Interquartile range; IQR = 12), following a median duration of epilepsy of 21.2 years (IQR = 13.3). Median time since surgery was 18.4 years (IQR = 4.3).

2.4. Data collection

In-depth, semistructured interviews of approximately 60–180 min (median = 86 min, IQR = 28) were conducted either face-to-face ($n = 7$) or via telephone ($n = 33$). There was no significant difference in length of interview according to modality (Table 1). While face-to-face is typically the preferred medium for qualitative research, studies have found telephone interviews comparable [33,34]. Telephone interviews were vital for our study in order to capture the typical patients who attend the Austin CEP, including those who lived rurally, interstate, or overseas.

Set questions and prompts were based on the *Austin CEP Interview*, a well-validated, psychosocial interview developed for epilepsy surgery patients by our group [3,4]. Some questions were slightly reworded to allow exploration of outcomes over a longer timeframe. In line with a grounded theory approach, prompts could be adjusted as the study progressed to explore emergent themes. For example, as the theme of an early period of postsurgical disequilibrium emerged, a prompt was included asking patients how long they felt this early period of adjustment, or their early postsurgical difficulties, lasted.

Following each interview, review of psychosocial follow-up records was conducted. This review was always conducted postinterview, in order to prevent any bias in the researcher’s approach to questioning. Memos reflecting researcher (H.C) observations and impressions from review of psychosocial follow-up records were included in the final analysis. Memos were also utilized in order to monitor reflexivity throughout the process of data collection and analysis.

2.5. Data analysis

Interviews were recorded and transcribed, and data were entered into NVivo 11 (QSR International Pty Ltd., Australia). Data analysis procedures were based on the systematic inductive–deductive method of grounded theory. As such, data analysis occurred concurrent with data collection, commencing after the first interview [24]. In the initial inductive stage, data are coded line by line to generate open, or *in vivo*, codes. Codes are strengthened or altered with each subsequent interview, and categories begin to form by clustering or condensing *in vivo* codes and identifying patterns across the data. This continues until a ‘‘core category’’ is identified, which reflects the overarching process in the data.

Table 1
Demographics and clinical of the final sample (n = 40).

Demographics	Mean (SD)/ n (%)
Gender	
Female	24 (60%)
Place of residence	
Victoria, Australia	18 (45%)
Interstate, Australia	19 (48%)
New Zealand	3 (7%)
Currently driving	
Yes	34 (85%)
Current marital status	
Single	5 (12%)
Partner	6 (15%)
Married	25 (63%)
Divorced/Widowed	4 (10%)
Current living situation	
Partner and/or children	31 (78%)
Parents	2 (5%)
Alone	7 (17%)
Highest level of education	
Primary school	2 (5%)
Secondary school	20 (50%)
Trade certificate	7 (18%)
University	11 (27%)
Current occupation	
Employed FT	19 (47%)
Employed PT	4 (10%)
Unemployed	14 (35%)
Retired	3 (8%)
AED regime at long-term follow-up	
None	8 (20%)
Monotherapy	22 (55%)
Polytherapy	10 (25%)
Side of resection	
Left	26 (65%)
Right	14 (35%)
GTCs presurgery	
Yes	15 (37%)
No	25 (63%)
Length of follow-up (SD)	17.9 years (2.5)
Age at regular seizure onset (SD)	12.4 years (9.7)
Age at surgery (SD)	32.8 years (8.6)
Duration of epilepsy (SD)	20.6 years (10.2)
Time since last seizure (SD)	11.6 years (7.8)
Duration of interview (SD)	
Telephone	91.2 min (29.0)
In person	91.1 min (40.6)

Note. AED = antiepileptic drug; FT = full-time; GTCs = generalized tonic-clonic seizures; PT = part-time; SD = standard deviation.

Theoretical saturation is achieved when additional data scrutiny yields no new codes or categories. The deductive stage then involves reanalysis of the original data set, coding for the core category, and main underlying themes and subthemes. Initial data analysis was conducted by H.C. and the final model, including core category and themes, was agreed upon in discussion with S.J.W and A.M.

2.6. Ethics

This study was approved by the Human Research Ethics Committees of Austin Health and The University of Melbourne. All patients gave informed consent in accordance with the Declaration of Helsinki. Transcribed interviews were deidentified and kept in a password protected folder, separate to patient medical records.

3. Results

3.1. A process of postsurgical meaning-making

The core category, or main process identified in the patient narratives, was one of meaning-making. Patient narratives demonstrated

that surgery was a major life turning point, and there was a need to make meaning of the decision to undergo surgery given the changes it brought and the impact it had on postsurgical psychosocial functioning. Main themes and subthemes underlying this core category are shown in Fig. 1.

Evident from these themes, meaning-making was triggered following surgery when patients experienced a sense of disequilibrium, or change, in their psychosocial functioning. Narratives at long-term follow-up reflected a reestablished sense of normality, achieved through this meaning-making process. A number of common psychological coping strategies were evident across narratives, assisting patients to reestablish a sense of normality, after the initial period of disequilibrium. Reflecting different long-term psychosocial trajectories, systematic differences were evident in the final narrative that patients presented at interview. These features reflected differences in the degree to which patients felt that surgery had changed their sense of self, and the extent to which they had engaged with the meaning-making process. Illustrative quotes are provided in-text, with further supporting quotes in Supplementary Tables 1 and 2.

3.2. Surgery as a major turning point

Turning points are often best identified in hindsight, when an individual reflects on his/her life journey and identifies a clear change of course. At long-term follow-up, surgery was an easily time-tagged event, with a clear demarcation between pre- and postsurgical life for many patients.

P2: I'm just so pleased that I had the surgery and would never want to go back to the way it was, you know?

3.2.1. Hope versus risk

The language used to describe surgery also highlighted the potential for it to drastically change patient lives. Surgery was a "chance at cure" or a "better life," and an opportunity that patients felt "lucky" or "blessed" to have.

P9: If you're given that opportunity that [surgery] may reduce them or stop them altogether, that's just, that's just a blessing. That's like you can get a second chance at having a better life.

This phrasing emphasizes the tenuous nature of patient hopes and expectations for improvements postsurgery, balanced against the risks and the possibility of a suboptimal outcome.

P10: I also had to think well, what repercussion will it have on [...] my mum and dad if something goes wrong [...] and they have to look after me.

3.2.2. Surgery as a final resort

Surgery could also be an important turning point because it followed a particularly low presurgical period involving the disheartening and frustrating process of trying multiple ineffective antiepileptic drugs (AEDs). In this context, some patients described surgery as a "final resort," somewhat negating the patient's active role in seeking out and/or choosing surgery. Patients perceived they had "no choice" but to undergo surgery, and therefore, the subsequent outcomes were inevitable. As one patient said,

P6: I wouldn't have done it if there had been any other option.

3.3. Early period of disequilibrium

Following surgery, many patients were thrown into a state of disequilibrium as they negotiated the strangeness of seizure freedom,

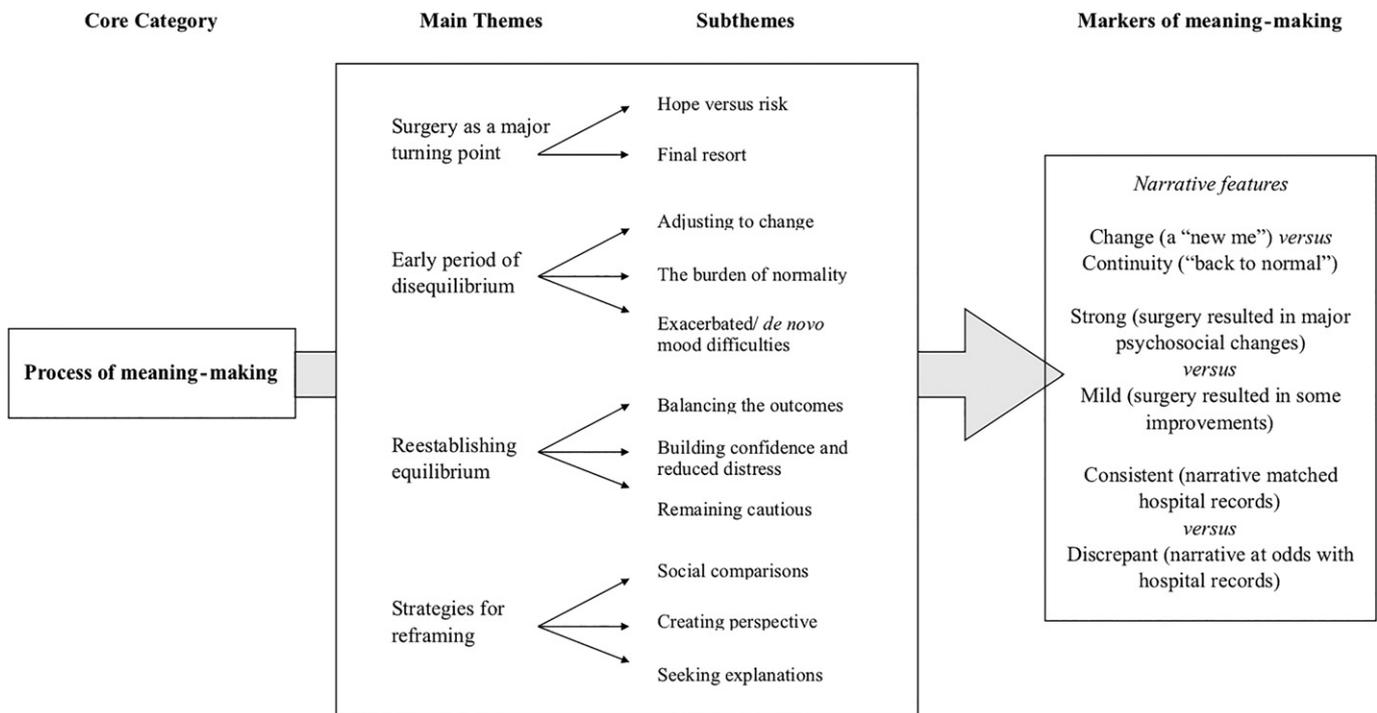


Fig. 1. Conceptual map of the data, including the core category and underlying main themes and subthemes.

faced the uncertainty of breakthrough seizures or the disappointment of regular seizure recurrence. The suddenness of this transition was described by one patient as,

P9: You go from can't work, can't drive, multiple seizures and a very limited social life and just very limited life to 'it's all ok, off you go.' Very strange.

3.3.1. Adjusting to change

This state of disequilibrium brought about a need to adjust to the change. For some patients, this was a relatively smooth process that involved exploring new social opportunities. However, for others, the period of postsurgical disequilibrium was challenging and involved significant adjustment (Section 3.3.2) or psychiatric difficulties (Section 3.3.3).

3.3.2. The burden of normality

Many patients described the process of adjusting to seizure freedom or a reduction in seizures in terms of features of the burden of normality [3,4]. They recalled a process of questioning their identity as a result of the sudden cessation of seizures and the flow-on effects for their psychosocial well-being. This included a sense of increased expectations on themselves and from others, a need to catch up on lost time, changes in their social and vocational opportunities, and a shift in their family dynamics.

P5: I was on fast-forward, I was sort of catching up everything that I'd missed. Relationships and all that. And socialising.

3.3.3. Exacerbated or *de novo* mood difficulties

In hindsight, patients felt that the postsurgical period of adjustment lasted between two and five years and was considered by many to be one of the most difficult periods of their lives. This could involve the onset or exacerbation of psychopathology. Some felt that existing symptoms of anxiety or depression “hit harder” following surgery, while others felt that unrecognized psychiatric symptoms, previously

masked by seizures and/or the side effects of AEDs, became unexpectedly salient.

P13: I got a lot of panic attacks immediately after the surgery. I mean I wasn't worried at all about the surgery but obviously subconsciously I was.

3.4. Reestablishing equilibrium

At long-term follow-up, patient narratives reflected a sense of having achieved stability and normality. In other words, they had reestablished a sense of equilibrium in their psychosocial functioning.

3.4.1. Balancing the outcomes

All patients reported that undergoing surgery was the right decision for them. Therefore, the process of reestablishing equilibrium involved balancing the positive and negative outcomes of surgery in light of this viewpoint. The general positive and negative long-term outcomes described by our cohort are consistent with previous studies [9,17,35,36]. Negative outcomes included suboptimal seizure outcome, memory problems, neurological outcomes such as migraine or numbness, lasting changes in family dynamics, and/or psychopathology. Positive outcomes related to alleviation or reduction of seizures, reduced worry, increased confidence, and new social and vocational opportunities.

P2: Even though I'm not [completely] seizure free, at least I don't have to deal with all the auras and whatnot. And absences that I would feel, and of course now too I can drive, whereas pre-surgery I couldn't.

3.4.2. Building confidence and reduced distress

Positive outcomes appeared to be strengthened over time as concern about possible seizure recurrence faded, confidence grew, and patients made increasing social gains [23]. In contrast, patients often adapted to the negative outcomes, with many reporting they were “used to”

memory issues, minor neurological complications, and/or seizure recurrence.

P17: [I thought] just because I've gone 6 months without [a seizure] doesn't mean I won't have one in a month's time. [...] But after all these years now, I'm confident that it's not going to happen again.

While patients acknowledged the difficulty of the early period of disequilibrium, there was a softening of the severity of issues when recalled at the time of long-term follow-up. Reduction in the severity of psychiatric symptoms over time was also evident through patient report of a decreasing need for professional support. If patients were engaged with a psychologist or psychiatrist at the time of long-term follow-up, it was predominantly for review rather than regular therapeutic input. This likely reflected a reduction in patient distress over time as they moved towards reestablishing a sense of equilibrium. Two patients who experienced particularly poor psychiatric outcomes postsurgery, however, felt that these difficulties presented more of a challenge to their social life and well-being than managing seizures pre- or postsurgery.

3.4.3. Remaining cautious

Despite reduced concern about seizure recurrence, there was typically no single 'moment of cure.' Rather, patients reported ongoing reflection on their seizure status, including caution about possible recurrence. This process was managed through practical and/or emotion-focused coping strategies. Practical strategies included limiting alcohol intake, maintaining general health and getting enough sleep, while emotion-focused strategies included "thinking positively." This caution may, in part, be due to the realistic postoperative counseling provided through the CEP. For instance, one patient felt she should not say she was cured, even though she considered herself to be.

P21: [I drink] a lot less since the operation. I mean it's, truthfully, it's a bit of a scare that if I drink too much I might have [a seizure], so that really works on me more than anything.

3.5. Strategies for reframing

The process of reestablishing equilibrium was more involved, however, than weighing up positive and negative outcomes. To help reestablish a sense of normality, patients drew on common psychological coping strategies.

3.5.1. Social comparisons

Comparisons made against friends and family allowed patients to establish a sense of normality or "typical" life — better than some, worse than others. Such comparisons could lessen the impact of negative postsurgical outcomes; for example, patients commonly explained the experience of memory difficulties as a natural part of aging, also experienced by friends and family, rather than an outcome of surgery.

P6: I talk to friends around the place and they sound like their memory's up the creek too, so [...] that makes you feel better.

Downward comparisons against unknown "others" also buoyed up perceived well-being with a general sense that "there's always someone worse off."

Social comparisons could also negatively highlight experiences not shared by family and/or friends, such as increased levels of fatigue. Many patients felt they became more cognitively fatigued than spouses or family members, sometimes also leading to reduced frustration tolerance. Upward comparisons could also highlight "losses" when comparing oneself with peers, such as not being able to work or have children. One patient still restricted by ongoing seizures said,

P25: If you don't have a license, really you can't get around and yeah, how else can you describe it? They [friends] work, I don't.

Social comparisons made against other people with epilepsy were an important tool for reinforcing the decision to undergo surgery. Encounters with others at the CEP who were unable to have surgery reinforced how "lucky" our cohort was to be eligible for surgery.

P20: I know there was a girl [...] that got told that an operation wouldn't work for her and, you know, I would have been gutted if that was me.

Comparisons with other people with epilepsy, either in public, known to the patient, or encountered at the CEP, also helped to minimize perceived severity of pre- or postsurgical epilepsy. These comparisons were dependant on the patient's own experiences. For example, one patient felt lucky to have later-onset epilepsy, while another was glad to have experienced epilepsy since birth after witnessing the adjustment difficulties a friend faced with adolescent-onset epilepsy. Social comparisons continued at the time of interview, with many enquiring about the outcomes of other study participants to gauge the normality of their own experiences.

P9: I'm really curious to know, like with other people that you get to speak to, if they had similar [outcomes]?

3.5.2. Creating perspective

Patients also described gaining new perspectives and a sense of increased positivity, often through comparisons with a past self.

P39: I've just got that brighter outlook on things [...] I've benefitted a lot with [surgery]. Yes, I really have, compared to what I was like.

This was commonly associated with increasing confidence in the surgical outcome over time. Creating a sense of progress over time could also help patients reframe suboptimal outcomes of surgery. For instance, seizure recurrence could be positively reframed by identifying psychosocial outcomes and increased well-being that accompanied reduced seizure frequency and/or fewer AEDs.

The development of new perspectives was an important outcome of the dynamic nature of the model. New perspectives on the experience of undergoing surgery could arise following subsequent major life events. For example, a few patients who experienced major illnesses following surgery, including cancer, felt that their experiences with epilepsy surgery made them better able to cope with subsequent challenges and further medical procedures.

P9: I guess [...] it makes me deal with everything that I've had [...] thrown at me and I've had cancer scares, I've had everything [...] it made me realise [that] no matter what happens to me, [...] if I could conquer that operation and learn everything again, well then!

Interestingly, a sense of progress also extended to the CEP, with many patients commenting on the progress of research and technology since they underwent surgery. This further highlighted surgery's status as a major turning point because it was not only a critical event in patient lives, but also the patients were part of an important chapter in the history of the CEP. One patient specifically commented that being in the early surgical cohort at Austin Health made her feel "special."

3.5.3. Seeking explanations

An important part of the meaning-making process was a need to explain postsurgical changes. Many patients sought alternative explanations to account for negative outcomes such as poor postsurgical adjustment or memory difficulties. Some of these were common across patients and reflected generic explanations. For example, memory difficulties were often attributed to busier lifestyles and/or aging.

P18: I don't think it's [memory difficulties] got to do with the operation, I think it's just I'm getting older and having kids.

Some common explanations were also evident for positive postsurgical outcomes, pointing towards the decreasing salience of surgery in patient lives over time. For example, at the time of interview, age and maturity became common explanations for increased confidence and reduced anxiety.

P31: Just my confidence has built over time but I think that's just age as well, [...], maturity with age as well.

Some explanations were more specific to the individual. This particularly occurred when patients sought to explain challenging postsurgical adjustment difficulties. Potentially other life events or experiences were drawn on to explain these difficulties so as not to attribute them directly to surgery, which they considered the right decision at long-term follow-up. For example, one patient felt that the emergence of postoperative depression within six months of surgery was a result of underlying marital unhappiness, despite no mention of marital difficulties in the psychosocial follow-up records at the time.

3.6. Narrative features

Following surgery, patients could experience significant changes in their social situation, intimate relationships, psychiatric status, and sense of self. The integration of these outcomes into a coherent narrative could be considered the 'outcome,' albeit a dynamic outcome, of the process of meaning-making. A number of systematic differences were identified in the narratives that patients presented at the time of follow-up. These were termed *Narrative Features* and included the type and strength of the narrative, as well as the presence of discrepancies between patient narratives at the time of interview and their hospital psychosocial follow-up records. In the current model, narrative features were conceptualized as indicators of patient engagement with the process of meaning-making, therefore, representing 'markers' of the core category (Fig. 1).

3.7. Narrative type

Two types of narratives were evident: change and continuity. A *change* narrative reflected establishment of a 'new normal,' a sense of being a new or different person after surgery. Change narratives were predominantly positive, and the 'new me' was someone more confident, independent, and able to take on new challenges. The identification of positive progress in internal attributes, such as confidence, assisted in the development of change narratives.

P39: I'm a different person [...] I can remember what I was like back years ago and yeah, I'm more than happy, and I [can] just never ever thank the doctors enough for what they did for me.

Change narratives were not all positive, however, and there were some patients who felt that they had become quieter, more anxious, or less able to handle stress following surgery.

P22: I'm a completely different person [...] I haven't worked since 2009 [...] and I'll probably never work again. Just because of the fatigue and um, I can't cope with stress.

The sense of a "new me" is core to the early process of identity reconceptualization that gives rise to features of the burden of normality. These features were evident in the early psychosocial records of our cohort, with expressions of feeling like a 'new me' recorded in the first 12 months after surgery. Some patients with a change narrative expressed remnant symptoms of this adjustment process at the long-term follow-up interview, particularly increased self-expectations and a feeling that epilepsy had held them back [3,4]. At the time of

interview, however, these symptoms no longer prompted major mood or behavioral changes, such as overactivity. Patients also appeared less quick to attribute these features directly to surgery as they had in the early adjustment period. For example, high standards were reframed as personality traits rather than increased self-expectations in the face of seizure freedom.

A *continuity* narrative was one of 'back to normal' or 'same as always.' A sense of continuity was typically achieved by drawing links to the presurgery self.

P1: I think I'm still the same person I was with seizures. But just not having that worry that something might happen, be it at work or out or anything like that.

As our adult sample was characterized by patients with predominantly early-onset epilepsy [$M = 12.4$ years, standard deviation (SD) = 9.7], this involved minimization of the impact of epilepsy prior to surgery, such that postsurgical life without epilepsy was not a major adjustment. Surgery, therefore, represented a turning point in the management of their epilepsy, which allowed for positive progress to be made in social milestones such as driving, but otherwise did not result in a major process of self-change and/or self-discovery.

P18: I think the only thing [surgery] changed like I said was, you know, I could just get a license now and not worry about it.

For some patients, however, who experienced epilepsy onset in their mid- to late twenties, a sense of continuity reflected connecting with preepilepsy strengths and the ability to overcome adversity, which aided coping with seizure recurrence postsurgery. For those who experienced a suboptimal outcome postsurgery, the sense of continuity related to "getting on with it" in the face of recurrent seizures.

P28: You know, 'Suck it up, [P28], get on with life.

Based on early hospital psychosocial records, expressions of feeling "back to normal" appeared to emerge earlier for patients with a successful seizure outcome who were able to create a sense of continuity sooner. For those who experienced early sporadic seizure recurrence, uncertainty about the extent of recurrence appeared to hamper the ability to 'get on with it,' resulting in a longer period of acceptance of ongoing seizures.

3.7.1. Narrative strength

Strong narratives were provided more spontaneously, appeared more considered, and were characterized by more strident statements that emphasized the significance of the surgery. For example, some patients described surgery as a process of "rebirth" or stated that surgery was the "only chance of survival." Patients with strong narratives also required less prompting to consider the impact of surgery on their sense of self, relationships, and social horizons, suggesting a link between strong narratives and narratives of change.

P32: I was very lucky because that was like opening the door for me. So when they offered me brain surgery, even though I was scared of it, it was the only chance I had of survival.

In contrast, *mild* narratives were less well articulated, often involving shorter answers. These patients required more prompting to reflect on the impact of surgery on their psychosocial outcomes.

3.7.2. Narrative discrepancies

Narrative discrepancies were identified by reviewing hospital psychosocial records relative to the long-term interview. This feature refers to discrepancies in the overall perspective, or *gestalt* of the narrative, rather than to the correct reporting of specific details, such as dates or names. While the severity of postsurgical adjustment difficulties was often softened in hindsight, many patients still presented an accurate

account of their early postsurgical trajectories as noted in the hospital records. For others, however, there was significant reframing, minimization or omission of postsurgical adjustment difficulties that had been documented in the psychosocial records. In some cases, this appeared to reflect an extensive process of seeking alternative explanations. For example, one patient who experienced significant mood and adjustment difficulties and marital conflict spanning up to five years postsurgery, reframed this as postsurgical hormonal difficulties. The opposite, although uncommon, could also occur, with patients reporting an extremely challenging postsurgical period despite hospital records noting a relatively smooth adjustment process.

3.8. A model of postsurgical meaning-making

Fifteen to 20 years after surgery, patient narratives were characterized by a dynamic and cyclical process of reflection and a process meaning-making triggered by the experience of undergoing surgery (Fig. 2). Patients reflected on the early postsurgical adjustment period and associated sense of psychological disequilibrium, which lasted up to five years. At long-term follow-up, a process of reflection and meaning-making was evident, through which patients were able to reestablish equilibrium, or a sense of normality. For some, a new normal was established through self-discovery and self-change, while others reported feeling back to their old selves. These narratives could then be strengthened as patients continued to revisit and reflect on their experiences of undergoing surgery and subsequent psychosocial adjustment. This ongoing reflection and meaning-making also allowed new or altered perspectives on surgery and its outcomes to be integrated into the narrative over time. For some patients, this altered perspective and the process of seeking to explain postsurgical changes led to notable discrepancies between the narratives presented at long-term interview and the psychosocial records from the time.

4. Discussion

Using a grounded theory approach, we have developed a theoretical model describing how patients reflect on and make meaning of the experience of undergoing epilepsy surgery, 15 to 20 years later. This model provides a useful long-term framework and aligns with existing literature on the psychosocial outcomes of epilepsy surgery, as well as the broader literature on meaning-making and chronic illness [37].

4.1. Epilepsy surgery as a 'biographical disruption'

The concept of chronic illness as a biographical disruption has been extensively explored in sociological and psychological fields. The focus of this research has predominantly been on the impact of a chronic

illness diagnosis, such as arthritis or acquired brain injury, as an "assault on the individual's sense of identity" [38–40]. Epilepsy surgery, however, presents a novel subject of study in this field because of objectively positive changes, namely seizure reduction or cessation, which can, nevertheless, prompt psychological distress [3]. The current study set out to identify the longer-term impact of this disruption and how patients were able to reestablish a sense of normality.

4.2. Meaning-making to reestablish normality

Fifteen to 20 years on, our patients identified epilepsy surgery as a major life turning point, with the potential to result in lasting change in psychosocial functioning. At the time of long-term interview, these changes had become part of 'normal life,' either as a new normal established postsurgery or the return to presurgery normality. A process of meaning-making medical, cognitive, and psychosocial outcomes into a coherent narrative of postsurgical adjustment. Theories of meaning-making posit that people can reduce psychological distress and maintain emotional well-being by balancing expectations for the future against perceptions of their current life, past experiences, and their perceived ideal life [37,41].

Applying this specifically to epilepsy surgery, it has been well-established that it can be associated with a range of expectations for psychosocial change [17,42–45], and that surgery can change patient perceptions of themselves and their psychosocial situation postoperatively [3,46,47]. In our model, this disruption was captured in the 'early period of disequilibrium,' including features of the burden of normality in many patients [3,4]. Patients described both positive experiences of increased independence and self-confidence, reduced worry about seizure recurrence, and new social horizons, as well as the negative experiences of family conflict and de novo or exacerbated psychiatric outcomes [3–5,27]. The consistency with which patients described these symptoms up to 20 years after surgery, and the perception among patients that the adjustment process lasted two to five years, provides strong support for the utility of this early framework in guiding pre- and postsurgery psychosocial rehabilitation [8].

Following the acute adjustment period, our model shows patients moving into a phase of reestablishing equilibrium and creating a sense of normality. This drive towards equilibrium is adaptive and helps to reduce psychological distress [37]. It can be achieved by (i) dynamically adjusting expectations and perceptions of one's current life, (ii) promoting a restored or altered sense of meaning, (iii) reappraising the meaning of the event, and/or (iv) identifying positive life changes [37,41,48]. These aspects of meaning-making are consistent with commonly described psychological coping mechanisms that our cohort used in order to reframe the outcomes of their surgery and create coherent

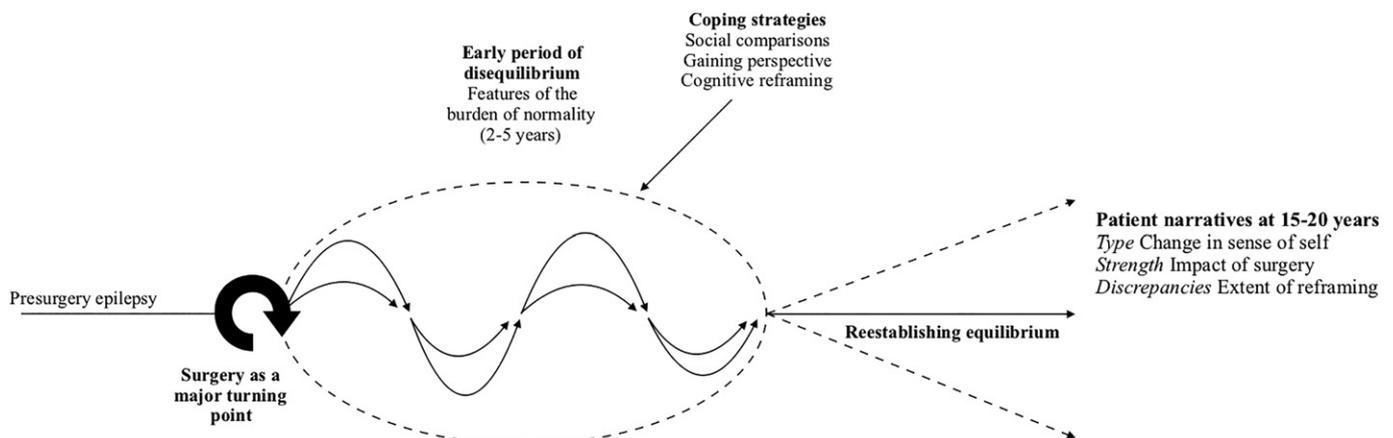


Fig. 2. Diagram of the dynamic process of postsurgical meaning-making.

narratives. Reduced distress as a result of this process was evident from decreased patient use of psychological or psychiatric support over time.

Previous research has suggested that a “product” of the meaning-making process is a sense of changed identity or integration of the disruptive experience into one's identity [37]. A qualitative study by Ozanne and colleagues described patient expectations of wanting to “get their lives back” and live as normally as possible approximately 13 years following epilepsy surgery. They also found that after surgery, seizure freedom and reduced worry about seizure recurrence gave patients the sense of having a “new life” [17]. We found that patients tended to favor one of these two narrative ‘types’ – either the idea that they were able to return to normal or the idea that they were able to establish a ‘new normal.’ This new normal reflected an altered self-identity as a result of undergoing surgery and suggests that while early symptoms of the burden of normality may resolve, the underlying identity reconceptualization can stabilize and represent a long-lasting outcome of surgery [3].

An important consideration for this model is that the decision to undergo surgery is voluntary [49]. Motivation to alter one's perceptions and/or expectations is heightened when we consider ourselves to have heightened responsibility for the decision and/or when faced with information that suggests we have made a poor choice [50]. For example, patients who stated that surgery was a final resort fostered an external locus of control, which may lessen their perceived responsibility for unexpected outcomes of surgery, such as fractured family dynamics.

An increased need to revisit an event is also thought to be impacted by its ongoing implication(s), the individual's need to interpret the meaning or personal significance of it, as well as social responses to its occurrence [50]. A challenging postsurgical adjustment process, involving more personally significant and social upheaval, may therefore prompt an increased need to find meaning and justify the decision to undergo surgery. In our model, this was captured by the strength of the narrative. Increased strength was thought to reflect increased need to revisit the meaning of undergoing surgery and its subsequent effects on psychosocial functioning. As such, patients who experience more challenges in the early period of disequilibrium, and those who perceived greater significance of surgery for their sense of self, were often more likely to have strong narratives.

Finally, narrative discrepancies were posited to arise because of the cyclical nature of the meaning-making process, and the integration of new information and ongoing reframing of postsurgical experiences. This feature may represent the engagement of protective cognitive biases that allow patients, through extensive reframing, to view surgery in a positive light, despite experiencing early postsurgical difficulties.

4.3. Clinical utility of a model of meaning-making

Our findings extend upon early work describing the short-term postsurgical adjustment period [3,8], thereby improving clinician understanding of the process of long-term postsurgical adjustment. This information is useful for presurgical counseling and expectation management for patients and families as well as postsurgical psychosocial follow-up [37,45,51–54]. For example, it can be reassuring and empowering for patients to know that undergoing a process of adjustment is ‘typical’ after surgery, and that while initially turbulent, this process is largely resolved within a five-year period. Understanding individual differences in long-term psychosocial trajectories, and bearing in mind the active role that patients play in their longer-term adjustment, will also enable clinicians to adopt a truly ‘patient-centered’ approach to this work.

4.4. Study strengths and limitations

While this study provides new insights into how patients make sense of the outcomes of their surgery, it is limited to those who have

undergone ATL. Our patients are likely to have experienced better seizure outcomes than patients who undergo extratemporal resections [55]. However, as TLE is the most common drug-resistant form of epilepsy for which surgery is preferred [56], this cohort is ideal for an initial exploration of long-term psychosocial outcomes. Moreover, within our study, we recruited patients with both optimal and suboptimal seizure outcomes.

Another important consideration is the report of memory difficulties among patients and the impact these may have had on the accurate reporting of long-past events. We believe, however, that the final model proposed remains robust as it represents patients' own perceptions of surgery, and discrepancies between the narratives and objective hospital records were captured as part of the model. Researchers have successfully examined meaning-making in other neurological populations, including schizophrenia and dementia [57,58]. Whether the discrepancies identified here reflect a fundamental memory issue, or whether this is a mechanism for maintaining well-being, is a question for ongoing research.

5. Conclusion

This study provides important insights into how patients make sense of the outcomes of their epilepsy surgery. Our model is consistent not only with findings from the epilepsy surgery literature but also the wider psychological and sociological literature on the impact of chronic illness on an individual's sense of self and well-being. Our findings also provide clinically relevant information for counseling patients pre- and postsurgery about the different stages of psychosocial adjustment and various trajectories patients can take over the longer term.

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Ethical publication statement

We confirm that we have read the Journal's position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

Declaration of competing interest

None to report.

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References

- [1] Wiebe S, Blume WT, Girvin JP, Eliasziw M. A randomized, controlled trial of surgery for temporal-lobe epilepsy. *N Engl J Med* 2001;345:311–8.
- [2] Shirbin CA, McIntosh AM, Wilson SJ. The experience of seizures after epilepsy surgery. *Epilepsy Behav* 2009;16:82–5.
- [3] Wilson S. The “burden of normality”: concepts of adjustment after surgery for seizures. *J Neurol Neurosurg Psychiatry* 2001;70:649–56.
- [4] Bladin PF. Psychosocial difficulties and outcome after temporal lobectomy. *Epilepsia* 1992;33:898–907.

- [5] Wilson SJ, Bladin PF, Saling MM, McIntosh AM, Lawrence JA. The longitudinal course of adjustment after seizure surgery. *Seizure* 2001;10:165–72.
- [6] Téllez-Zenteno JF, Wiebe S. Long-term seizure and psychosocial outcomes of epilepsy surgery. *Curr Treat Options Neurol* 2008;10:253–9.
- [7] Spencer S, Huh L. Outcomes of epilepsy surgery in adults and children. *Lancet Neurol* 2008;7:525–37.
- [8] Wilson SJ, Bladin PF, Saling MM. The burden of normality: a framework for rehabilitation after epilepsy surgery. *Epilepsia* 2007;48(Suppl. 9):13–6.
- [9] Andersson-Roswall L, Engman E, Samuelsson H, Malmgren K. Psychosocial status 10 years after temporal lobe resection for epilepsy, a longitudinal controlled study. *Epilepsy Behav* 2013;28:127–31.
- [10] Hamiwka L, Macrodimitris S, Téllez-Zenteno JF, Metcalfe A, Wiebe S, Kwon C-S, et al. Social outcomes after temporal or extratemporal epilepsy surgery: a systematic review. *Epilepsia* 2011;52:870–9.
- [11] Dupont S, Tanguy M-L, Clemenceau S, Adam C, Hazemann P, Baulac M. Long-term prognosis and psychosocial outcomes after surgery for MTLE. *Epilepsia* 2006;47:2115–24.
- [12] Malmgren K, Edelvik A. Long-term outcomes of surgical treatment for epilepsy in adults with regard to seizures, antiepileptic drug treatment and employment. *Seizure* 2017;44:217–24.
- [13] Jones JE, Blocher JB, Jackson DC. Life outcomes of anterior temporal lobectomy: serial long-term follow-up evaluations. *Neurosurgery* 2013;73:1018–25.
- [14] Mathon B, Bielle F, Samson S, Plaisant O, Dupont S, Bertrand A, et al. Predictive factors of long-term outcomes of surgery for mesial temporal lobe epilepsy associated with hippocampal sclerosis. *Epilepsia* 2017;58:1473–85.
- [15] Taft C, Sager Magnusson E, Ekstedt G, Malmgren K. Health-related quality of life, mood, and patient satisfaction after epilepsy surgery in Sweden – a prospective controlled observational study. *Epilepsia* 2014;55:878–85.
- [16] Reid K, Herbert A, Baker GA. Epilepsy surgery: patient-perceived long-term costs and benefits. *Epilepsy Behav* 2004;5:81–7.
- [17] Ozanne A, Graneheim UH, Ekstedt G, Malmgren K. Patients' expectations and experiences of epilepsy surgery: a population-based and long-term qualitative study. *Epilepsia* 2016;57:605–11.
- [18] Edelvik A, Taft C, Ekstedt G, Malmgren K. Health-related quality of life and emotional well-being after epilepsy surgery: a prospective, controlled, long-term follow-up. *Epilepsia* 2017;58:1706–15.
- [19] 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.
- [20] 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;20:764–74.
- [21] Hosseini N, Sharif F, Ahmadi F, Zare M. Patients' perception of epilepsy and threat to self-identity: a qualitative approach. *Epilepsy Behav* 2013;29:228–33.
- [22] McEwan MJ, Espie CA, Metcalfe J, Brodie MJ, Wilson MT. Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods. *Seizure* 2004;13:15–31.
- [23] Coleman H, McIntosh AM, Wilson SJ. Identifying the trajectory of social milestones 15–20 years after epilepsy surgery: realistic timelines for postsurgical expectations. *Epilepsia Open* 2019;4:369–81.
- [24] Glaser BG, Strauss AL. The discovery of grounded theory. Strategies for qualitative research. New Brunswick (USA): Aldine Transaction; 1967.
- [25] Glaser B. Doing grounded theory: issues and discussions. Mill Valley, CA: Sociology Press; 1998.
- [26] Stern PN, Porr CJ. Essentials of accessible grounded theory. Walnut Creek, CA: Left Coast Press; 2011.
- [27] Wilson SJ, Bladin PF, Saling MM, Pattison PE. Characterizing psychosocial outcome trajectories following seizure surgery. *Epilepsy Behav* 2005;6:570–80.
- [28] Velissaris SL, Saling MM, Newton MR, Berkovic SF, Wilson SJ. Psychological trajectories in the year after a newly diagnosed seizure. *Epilepsia* 2012;53:1774–81.
- [29] Jacoby A, Baker GA. Quality-of-life trajectories in epilepsy: a review of the literature. *Epilepsy Behav* 2008;12:557–71.
- [30] Jackson GD, Berkovic SF, Tress BM, Kalnins RM, Fabinyi GC, Bladin PF. Hippocampal sclerosis can be reliably detected by magnetic resonance imaging. *Neurology* 1990;40:1869–75.
- [31] Berkovic SF, McIntosh AM, Kalnins RM, Jackson GD, Fabinyi GCA, Brazenor GA, et al. Preoperative MRI predicts outcome of temporal lobectomy. *Neurology* 1995;45:1358–63.
- [32] Starks H, Trinidad SB. Choose your method: a comparison of phenomenology, discourse analysis, and grounded theory. *Qual Health Res* 2007;17:1372–80.
- [33] Sturges JE, Hanrahan KJ. Comparing telephone and face-to-face qualitative interviewing: a research note. *Qual Res* 2004;4:107–18.
- [34] Holt A. Using the telephone for narrative interviewing: a research note. *Qual Res* 2010;10:113–21.
- [35] Stavem K, Bjørnaes H, Langmoen IA. Long-term seizures and quality of life after epilepsy surgery compared with matched controls. *Neurosurgery* 2008;62:326–35.
- [36] Elsharkawy AE, Thorbecke R, Ebner A, May TW. Determinants of quality of life in patients with refractory focal epilepsy who were not eligible for surgery or who rejected surgery. *Epilepsy Behav* 2012;24:249–55.
- [37] Park CL. Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. *Psychol Bull* 2010;136:257–301.
- [38] Williams G. The genesis of chronic illness: narrative re-construction. *Social Health Illn* 1984;6:175–200.
- [39] Gracey F, Palmer S, Rous B, Psaila K, Shaw K, O'Dell J, et al. "Feeling part of things": personal construction of self after brain injury. *Neuropsychol Rehabil* 2008;18:627–50.
- [40] Ownsworth T. Self-identity after brain injury. Psychology Press; 2014.
- [41] Headey B, Wearing AJ. Understanding happiness. Melbourne, Australia: Longman Cheshire; 1992.
- [42] Taylor DC, McMackin D, Staunton H, Delanty N, Phillips J. Patients' aims for epilepsy surgery: desires beyond seizure freedom. *Epilepsia* 2001;42:629–33.
- [43] Baxendale S, Thompson PJ. "If I didn't have epilepsy ...": patient expectations of epilepsy surgery. *J Epilepsy* 1996;9:274–81.
- [44] Wilson SJ, Saling MM, Lawrence J, Bladin PF. Outcome of temporal lobectomy: expectations and the prediction of perceived success. *Epilepsy Res* 1999;36:1–14.
- [45] Wheelock I. Expectations and life changes associated with surgery for intractable epilepsy. *J Epilepsy* 1998;11:48–57.
- [46] Dewar SR, Pieters HC. Perceptions of epilepsy surgery: a systematic review and an explanatory model of decision-making. *Epilepsy Behav* 2015;44:171–8.
- [47] Chin PS, Berg AT, Spencer SS, Lee ML, Shinnar S, Sperling MR, et al. Patient-perceived impact of resective epilepsy surgery. *Neurology* 2006;66:1882–7.
- [48] Headey B, Kelley J, Wearing A. Dimensions of mental health: life satisfaction, positive affect, anxiety and depression. *Social Indicators Res* 1993;29:63–82.
- [49] Baxendale S. When epilepsy surgery fails. *Epilepsy Behav* 2014;33:22–3.
- [50] Tait R, Silver RC. Coming to terms with major negative life events. In: Uleman JS, Bargh JA, editors. Unintended thought. New York: The Guilford Press; 1989. p. 351–82.
- [51] Baxendale S. Managing expectations of epilepsy surgery. In: Malmgren K, Baxendale S, Cross HJ, editors. Long-term outcomes of epilepsy surgery in adults and children. New York: Springer; 2015. p. 243–53.
- [52] Baxendale S. Neuropsychological assessment in epilepsy. *Pract Neurol* 2018;18:43–8.
- [53] Bally JMG, Holtslander L, Duggleby W, Wright K, Thomas R, Spurr S, et al. Understanding parental experiences through their narratives of restitution, chaos, and quest: improving care for families experiencing childhood cancer. *J Fam Nurs* 2014;20:287–312.
- [54] Sanderson T, Calnan M, Morris M, Richards P, Hewlett S. Shifting normalities: interactions of changing conceptions of a normal life and the normalisation of symptoms in rheumatoid arthritis. *Social Health Illn* 2011;33:618–33.
- [55] McIntosh AM, Averill CA, Kalnins RM, Mitchell LA, Fabinyi GCA, Jackson GD, et al. Long-term seizure outcome and risk factors for recurrence after extratemporal epilepsy surgery. *Epilepsia* 2012;53:970–8.
- [56] Engel J, McDermott MP, Wiebe S, Langfitt JT, Stern JM, Dewar S, et al. Early surgical therapy for drug-resistant temporal lobe epilepsy: a randomized trial. *Jama* 2012;307:922–30.
- [57] Berna F, Bennouna-Greene M, Potheegadoo J, Verry P, Conway MA, Danion J-M. Impaired ability to give a meaning to personally significant events in patients with schizophrenia. *Conscious Cogn* 2011;20:703–11.
- [58] Batra S, Sullivan J, Williams BR, Geldmacher DS. Qualitative assessment of self-identity in people with advanced dementia. *Dementia* 2016;15:1260–78.