

Understanding long-term changes in patient identity 15–20 years after surgery for temporal lobe epilepsy

Honor Coleman^{1,2}  | Anne McIntosh^{2,3}  | Genevieve Rayner^{1,2,4}  | Sarah J. Wilson^{1,2} 

¹Melbourne School of Psychological Sciences, University of Melbourne, Melbourne, Victoria, Australia

²Epilepsy Research Centre, Department of Medicine (Austin Health), University of Melbourne, Melbourne, Victoria, Australia

³Department of Medicine, Melbourne Brain Centre, Royal Melbourne Hospital, University of Melbourne, Melbourne, Victoria, Australia

⁴Department of Neuropsychology, Austin Health, Melbourne, Victoria, Australia

Correspondence

Honor Coleman, Melbourne School of Psychological Sciences, Redmond Barry Building, University of Melbourne, Parkville, Victoria 3052, Australia.
Email: honor.coleman@unimelb.edu.au

Abstract

Objective: Following epilepsy surgery, patients can experience complex psychosocial changes. We recently described a longer term adjustment and reframing (“meaning-making”) process 15–20 years following surgery for temporal lobe epilepsy, which could involve an ongoing sense of being a “different” person for some patients. Here, we quantitatively examine identity at long-term follow-up and how this relates to meaning-making and postoperative seizure outcome.

Methods: Eighty-seven participants were included: 39 who underwent anterior temporal lobectomy (ATL) 15–20 years ago (59% female; median age = 49.2 years, interquartile range [IQR] = 10; median follow-up = 18.4 years, IQR = 4.4) and 48 surgically naïve focal epilepsy patients (56% female; median age = 34.5 years, IQR = 19). We captured approach to meaning-making by coding for key narrative features identified in our previous qualitative work. Nonparametric tests and correspondence analysis were then used to explore relationships between a quantitative measure of identity and meaning-making, as well as seizure outcome, mood, and health-related quality of life (HRQOL).

Results: Patients 15–20 years post-ATL demonstrated a shift toward increasing identity commitment and exploration compared to the surgically naïve cohort, with this shift significantly linked to seizure outcome. Examining the relationship between identity and meaning-making also revealed three groups: (1) those who embraced self-change (29%), (2) those who continued to struggle with this process (60.5%), and (3) those who showed minimal engagement (10.5%). Those who “embraced change” were significantly younger at regular seizure onset and demonstrated a trend toward higher HRQOL.

Significance: Findings suggest that ATL patients show a more developed identity profile compared to surgically naïve controls; however, the majority still struggled with postoperative identity change at long-term follow-up. Approximately one third of patients demonstrated positive psychological growth following surgery, reflected in the ability to embrace change. Findings highlight the importance of

understanding the impact of surgery on patient identity to maximize the psychosocial benefits.

KEYWORDS

HRQOL, identity, long-term outcomes, meaning-making, psychosocial outcomes

1 | INTRODUCTION

Identity is an important psychological construct that encompasses an individual's memories, values, and self-perspectives, and a well-developed sense of self can foster greater self-esteem.^{1,2} Erikson's seminal theory of identity development posits that a unique sense of self emerges during adolescence through exploration of, and commitment to, important social roles and ideals.¹ Living with chronic epilepsy can alter this process and result in the illness becoming integrated into an individual's identity.³⁻⁵ In line with Erikson's theory, epilepsy onset prior to or during adolescence has been found to impact on identity development, with onset prior to adolescence associated with a less developed identity.⁴ This may be due to psychosocial restrictions and perceived stigma impeding the exploration of social roles.⁵⁻⁸ It may also reflect neurocognitive impairments associated with epilepsy such as poor autobiographical memory or social cognition,^{4,9,10} impeding the synthesis of previous experiences in the identity development process.

Challenges to an individual's identity following injury or illness onset can cause significant psychological distress.¹¹⁻¹³ Following successful epilepsy surgery, some patients undergo a process of identity reconceptualization as they learn to live without epilepsy, which can be associated with paradoxical but significant mood and adjustment difficulties.¹⁴⁻¹⁷ Aspects of this process, termed the "burden of normality," bear a resemblance to identity development as described by Erikson.^{1,2,14} For example, some patients engage in a flurry of overactivity to catch up on years "lost" to epilepsy,¹⁴⁻¹⁷ resembling a process of heightened identity exploration.

To date, research has predominantly focused on the early postsurgical adjustment process (≤ 5 years), with far less known about psychosocial adjustment over the long term (> 15 years).¹⁸ To address this gap, we recently conducted an in-depth, qualitative investigation of long-term adjustment trajectories following anterior temporal lobectomy (ATL) specifically focusing on how patients conceptualized and reframed their postsurgical psychosocial experiences through an active psychological process

Key Points

- Fifteen to 20 years post-ATL, patients showed a more developed identity profile compared to surgically naïve patients, linked to seizure outcome
- Examining markers of identity and meaning-making identified three subgroups: those who embraced change, struggled with change, or showed minimal change
- Patients who embraced the process of postoperative meaning-making and identity change reported higher HRQOL at long-term follow-up
- Those who embraced change were younger at seizure onset, with longer duration of presurgery epilepsy

of "meaning-making."^{17,19} For some patients, this included ongoing report of feeling like a "different" person following surgery. The current study expands upon our previous work by further exploring identity at long-term follow-up and how this relates to the meaning-making process, as well as seizure outcome, mood, and health-related quality of life (HRQOL).

Here, we quantitatively examine identity at long-term postsurgical follow-up relative to neurosurgically naïve patients, and explore how the process of meaning-making and postsurgical seizure outcome inform changes in identity. We utilize the Ego Identity Process Questionnaire (EIPQ), which includes dimensional measures of self-identity exploration and commitment and determines an individual's overall identity "status" based on these dimensions. At long-term postsurgical follow-up, we hypothesized that:

1. ATL patients would demonstrate greater levels of identity development relative to neurosurgically naïve patients.
2. A more developed identity status would be associated with (a) greater meaning-making postsurgery and (b) better long-term seizure outcome, mood, and HRQOL.

2 | MATERIALS AND METHODS

2.1 | Participants

Details of patient recruitment, inclusion criteria, and seizure classification have been detailed in previous publications.^{17,19} Briefly, 40 adults who had undergone ATL for temporal lobe epilepsy (TLE) were interviewed for a large qualitative study assessing long-term psychosocial outcomes.^{17,19} One patient was thought to have developed psychogenic nonepileptic seizures postsurgery and was a significant outlier on all quantitative self-report measures. This patient was therefore excluded, resulting in a final sample of 39 (23 female; 25 left-sided). This study was approved by the human research ethics committees of Austin Health and the University of Melbourne, Australia. All patients gave informed consent.

Postsurgery, patients underwent regular medical and psychosocial follow-up for 24 months, after which they typically received ongoing second yearly follow-up by telephone if there was no other contact with the Austin Health Comprehensive Epilepsy Program (CEP) in this time.^{20,21} Information relating to their progress and seizure outcome was documented by the CEP. This was used to classify seizure outcome as follows: (1) seizure-free (SF), with or without auras ($n = 10$, 26%); (2) mixed outcome (MO), including those with one or more periods of seizure freedom lasting ≥ 5 years ($n = 23$, 59%); or (3) ongoing seizures (OS), including those with no period of seizure freedom lasting ≥ 5 years ($n = 6$, 15%).

Neurosurgically naïve patients with drug-resistant focal epilepsy were utilized as a comparison group. These patients ($n = 51$) were recruited for Allebone et al.'s study⁴ on identity and autobiographical memory. Three were missing the relevant EIPQ data, which left $n = 48$ (56% female). Patient demographics can be seen in Table 1. Mann–Whitney U tests revealed a significant difference in age at seizure onset ($U = 577.5$, $p = .002$, $r = -.33$) and age at study ($U = 309.5$, $p < .001$, $r = -.57$).

2.2 | Materials

2.2.1 | Ego Identity Process Questionnaire

The EIPQ is a well-validated quantitative measure of identity exploration and commitment.^{1,22,23} Exploration describes the process of seeking and evaluating self-relevant interpersonal and ideological information, whereas commitment reflects deciding on a self-concept. Individuals are considered to progress through four identity "statuses" in a stepwise manner based on their level of exploration and commitment (see Figure S1).^{22,23} A *Diffused* identity status reflects a relatively immature identity, characterized

TABLE 1 Clinical and demographic information for the ATL and surgically naïve groups

Characteristic	ATL group, $n = 39$	Surgically naïve group, $n = 48$
Gender, n (%)		
Female	23 (59%)	27 (56%)
Currently driving, n (%)		
Yes	34 (87%)	9 (19%)
Current living situation, n (%)		
Partner and/or children	30 (77%)	24 (50%)
Parents	2 (5%)	15 (31%)
Shared	–	6 (13%)
Alone	7 (18%)	3 (6%)
Highest level of education, n (%)		
Primary school	2 (5%)	–
Secondary school	19 (49%)	18 (37%)
Trade certificate	7 (18%)	10 (21%)
University	11 (28%)	20 (42%)
Current occupation, n (%)		
Employed FT/PT	23 (59%)	24 (50%)
Unemployed	13 (33%)	24 (50%)
Retired	3 (8%)	–
Current AED regime, n (%)		
None	8 (21%)	–
Monotherapy	22 (56%)	13 (27%)
Polytherapy	9 (23%)	35 (73%)
Laterality, n (%)		
Left	25 (64%)	20 (42%)
Median age at regular seizure onset, years (IQR)	10.0 (14.0)	19.0 (13.5)
Median age at study, years (IQR)	49.2 (10.0)	34.5 (19.0)
Median age at surgery, years (IQR)	33.0 (12.0)	–
Median duration of presurgery epilepsy, years (IQR)	20.6 (13.1)	–
Median length of postoperative follow-up, years (IQR)	18.4 (4.4)	–
Median time since last seizure, years (IQR)	14.7 (16.0)	–

Note:: Unemployed includes home duties as well as unemployment benefits. The surgically naïve group consisted of 29 (60%) temporal lobe, eight (17%) frontal lobe, and five (10%) frontotemporal epilepsy, as well as six (13%) "other" (e.g., focal epilepsy of unknown origin). These patients are described in Allebone et al.⁴

Abbreviations: AED, antiepileptic drug; ATL, anterior temporal lobectomy; FT, full time; IQR, interquartile range; PT, part time.

by low exploration and commitment. This is followed by premature commitment to social roles and ideals without adequate exploration (*Foreclosed*), often reflecting the assumption of expected roles within a family or community group. *Moratorium* is an "active" state of exploring new and varied social roles without commitment, before a person reaches a mature identity characterized by sufficient levels of both exploration and commitment to one's identity (*Achieved*).

Participants rated 32 statements examining ideological (occupation, religion, politics, and values) and interpersonal (family, friendships, relationships, and gender roles) identity-related beliefs on a 6-point Likert scale. Two 16-item subscales represent the degree of identity exploration and commitment, with subscale scores ranging from 16 to 92. Higher scores indicate greater exploration or commitment. Example items include: "I have considered adopting different kinds of religious beliefs" (exploration) and "I am very confident about what kinds of friends are best for me" (commitment). Adequate reliability has been reported for both scales.^{22,24} For patients who missed four or fewer questions ($n = 7$), the mean response for the relevant scale was used to fill the missing item. One post-ATL patient missed five items on the EIPQ and was therefore excluded, leaving $n = 38$ for these analyses.

Healthy control data obtained in previous research from our group was used to determine median scores for commitment (median = 62.0) and exploration (median = 61.0), with these cutoffs used to classify patients according to the four statuses (see Figure 1).⁴ For example, a patient with higher commitment and exploration than both median values would be classified as Achieved. The healthy control group was recruited from the friends

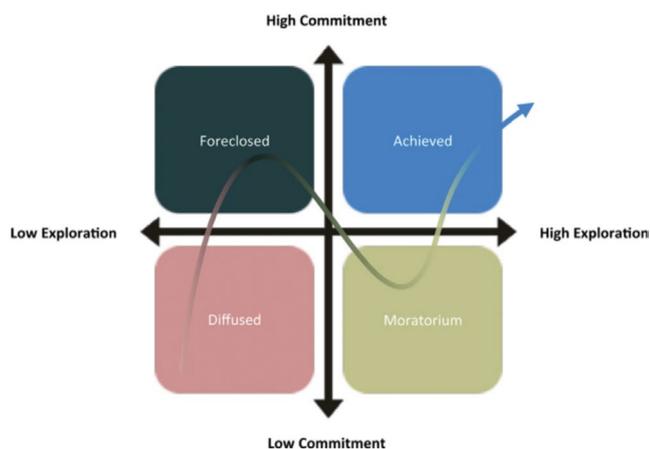


FIGURE 1 Depiction of the process of identity exploration and commitment. The arrow represents the normal process of identity formation, from identity diffusion (low exploration and commitment), to identity achievement (high exploration and commitment). Taken from Allebone et al.⁴

and family of focal epilepsy patients ($n = 51$; mean age = 37.43 years, SD = 12.96; 30 females).

2.2.2 | Patient approaches to meaning-making

Approach to meaning-making was coded across three distinct variables described in our previous research¹⁷: narrative type, strength, and discrepancies. These were derived from qualitative analysis of interviews with the ATL cohort.

The first meaning-making variable, narrative type, reflects whether patients feel like a "new" or "different" person postsurgery (a sense of "change"; 38% of patients).¹⁷ This compares to those who reported that life was "back to normal" following surgery, describing a sense of "continuity" (62% of patients).

The strength of the narrative reflects how much patients engaged with meaning-making to create a coherent account of their postsurgical experiences. For example, patients with "strong" narratives (41%) gave longer, more elaborate answers to interview questions, or provided an overview of the outcomes of their surgery without prompting. Those with "mild" narratives (59%) required more prompting to consider the impact of surgery on their sense of self and broader psychosocial functioning.

Narrative discrepancies reflect differences between the narratives presented by patients on interview and those documented in hospital psychosocial records early after surgery. For example, a patient may describe having had a relatively straightforward course of adjustment postoperatively, contrary to psychosocial records. Discrepancies were considered to reflect the role of protective cognitive biases as patients continued to reframe their experiences after surgery. There was a similar number of patients with "discrepant" versus "consistent" narratives (51% vs. 49%, respectively).

Narratives were coded according to the above binary categories by the first author (H.C.), based on the predominance of these themes within individual patient narratives. The process of coding and categorization was iterative and involved discussion and consensus with co-authors (A.M. and S.J.W.) to promote reflexivity and account for subjectivity.

2.2.3 | Mood and HRQOL

The Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) is a six-item screening measure for assessing symptoms of depression that do not overlap with the cognitive comorbidities of epilepsy or side effects of

antiepileptic drugs. Scores of >15 have been shown to have 90% specificity and 81% sensitivity for a diagnosis of major depression in epilepsy patients.^{25,26}

The Patient Health Questionnaire for Generalized Anxiety Disorders–7-item (PHQ-GAD-7) was used as a measure of anxiety. The PHQ-GAD-7 was validated in 2740 primary care patients and assesses the severity of symptoms of generalized anxiety disorder. The total score ranges from 0 to 21, with scores of 5, 10, and 15 representing cutoff points for mild, moderate, and severe anxiety, respectively.²⁷

The Quality of Life in Epilepsy–31-item questionnaire (QOLIE-31) is an abbreviated version of the QOLIE-89. Subscales focus on the emotional/psychological effects of epilepsy (seizure worry, overall quality of life, emotional well-being, and energy/fatigue) and the medical/social effects (effects of medication, work, driving and social restrictions, and cognitive function). Higher scores reflect better HRQOL. Subscales have been reported to have good internal consistency and test–retest reliability.^{28,29}

2.2.4 | Clinical and demographic variables

Clinical variables included age at habitual seizure onset, age at surgery, side of resection, postoperative seizure outcome (SF vs. MO vs. OS), and time since the most recent seizure. Demographic variables included gender, years of education, and current employment status.

2.3 | Data analysis

Due to the small sample size and nonnormal distribution of the data, conservative nonparametric tests were used to explore between-group differences, namely, Fisher exact test for categorical variables, and Mann–Whitney *U* or Kruskal–Wallis tests for continuous variables. Analyses were conducted using IBM SPSS Statistics (v24). All tests were two-tailed, with a chosen 5% significance level. Effect sizes were calculated using the method of Rosenthal for nonparametric tests.³⁰

To examine Hypothesis 1, the proportion of patients assigned to each identity status (Diffused, Foreclosed, Moratorium, Achieved) was contrasted against the proportion in the surgically naive cohort.⁴

Hypothesis 2(a) was examined in two ways. First, Fisher exact test was used to compare differences in the presence of each narrative feature (type, strength, discrepancies) for the four identity statuses in the ATL group. Second, the approach to meaning-making was examined by grouping ATL patients according to distinct combinations of their

narrative type, strength, and the presence/absence of discrepancies (Table S1).

A correspondence analysis then explored the relationship between these subgroups and the identity statuses. Correspondence analysis is a technique like principal components analysis but for categorical rather than continuous data. It allows for visualization of the data by examining the relative distances between variables. This provides a flexible exploratory data-mapping technique with few mandatory assumptions about data homogeneity.^{31,32}

To test Hypothesis 2(b), Pearson correlation analyses were run between the EIPQ subscales of exploration and commitment, the dimensional clinical and demographic variables, and ATL patient responses on the NDDI-E, PHQ-GAD-7, and QOLIE-31. Fisher exact test examined differences for the categorical variables for the identified subgroups, whereas Mann–Whitney *U* and Kruskal–Wallis tests examined subgroup differences on the continuous variables.

3 | RESULTS

3.1 | Identity status at long-term follow-up: A shift out of Diffused identity

Median scores for the EIPQ commitment and exploration scales for the ATL patients were 67 (interquartile range [IQR] = 14.3) and 52.5 (IQR = 17.2), respectively. The majority of patients were identified as having a Foreclosed identity status ($n = 26$, 68%), with the next most prominent group being Moratorium ($n = 7$, 18%), followed by a small number of patients in Diffused ($n = 3$, 8%) or Achieved ($n = 2$, 5%; Figure 2).

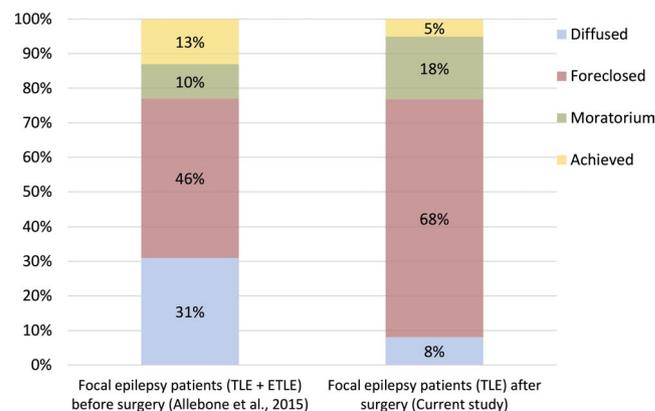


FIGURE 2 Anterior temporal lobectomy patient identity status 15–20 years after surgery ($n = 38$) compared to that reported by Allebone et al. in focal epilepsy patients before surgery ($n = 48$).⁴ ATL, anterior temporal lobectomy; ETLE, extra-temporal lobe epilepsy; TLE, temporal lobe epilepsy

For the surgically naïve group, median (IQR) scores for the EIPQ commitment and exploration scales were 64.5 (14) and 54 (13), respectively. This group was more evenly spread between the Foreclosed ($n = 22$, 46%) and Diffused ($n = 15$, 31%) identity statuses, with fewer in Moratorium ($n = 5$, 10%). Again, there were few patients with an Achieved identity status ($n = 6$, 13%).

Figure 2 indicates a shift in patient identity status at long-term postsurgical follow-up relative to the surgically naïve focal epilepsy patients, supported by a significant difference between the two groups ($\chi^2 = 9.67[3]$, $p = .019$, $\eta^2 = .11$, medium effect). Fifteen to 20 years post-ATL, there was a larger number of patients in Foreclosed (68% vs. 46% surgically naïve) and Moratorium (18% vs. 10% surgically naïve), with the data suggesting a shift out of Diffused identity (8% vs. 31% surgically naïve).

Identity status was also significantly associated with postoperative seizure outcome ($\chi^2 = 14.19[6]$, $p = .006$, $\eta^2 = .37$, large effect; Table 2), with all SF patients and the majority of MO patients identifying as Foreclosed. There were no other significant associations between identity status and clinical or demographic variables ($p > .05$ for all comparisons).

3.2 | Exploring the association between identity and meaning-making after ATL

Identity status was significantly associated with distinct aspects of meaning-making. Specifically, higher proportions of Foreclosed and Moratorium patients described a sense of self-continuity compared to self-change long-term postsurgery ($\chi^2 = 8.55[3]$, $p = .015$, $\eta^2 = .22$, large effect; Table 3). No significant associations were found between identity status and narrative strength or the presence of discrepancies with early psychosocial records ($p > .05$).

The relationship between identity status and overall approach to meaning-making was explored via correspondence analysis, allowing the combination of narrative type, strength, and discrepancies to be considered holistically. Correspondence analysis considers relative

TABLE 2 Relationship between Ego Identity Process Questionnaire identity status and seizure outcome

Identity statuses	Seizure-free, $n = 10$	Mixed outcome, $n = 23$	Ongoing seizures, $n = 5$
Diffused	0 (0%)	3 (13%)	0 (0%)
Foreclosed	10 (100%)	15 (65%)	1 (20%)
Moratorium	0 (0%)	5 (22%)	2 (40%)
Achieved	0 (0%)	0 (0%)	2 (40%)

Bolded numbers highlight the most prevalent identity status(es) for each seizure outcome group.

distances between and within groups of variables; as such, we were able to explore not only the relationship between approach to meaning-making and identity status but also the relative relationship between different approaches to meaning-making. This allows for the identification of groups with similar traits for further exploration.

An interesting and theoretically cogent pattern emerged from the analysis, with three main subgroups identified (Figure 3).

The predominant subgroup ($n = 23$, 60.5%) comprised patients who reported a sense of continuity postsurgery, including strong continuity narratives that were either consistent or discrepant with early psychosocial records (Figure 3). These approaches to meaning-making aligned with either a (1) prematurely Foreclosed identity status involving minimal identity exploration and a consistent continuity narrative, or (2) a state of Moratorium involving active exploration and a continuity narrative that appeared discrepant with psychosocial records. Combined, this group was labeled *Struggling With Change* to reflect the idea that ineffective engagement with meaning-making may be hampering identity change. For example, patients who reported a strong sense of continuity, consistent with their early psychosocial records, may have spent time reflecting on their postoperative experiences (as indicated by a stronger narrative), but surgery did not result in major psychosocial changes or prompt a desire to explore new social opportunities. In contrast, those with a strong continuity narrative that was discrepant with their early psychosocial records may be minimizing or avoiding reflecting on the experiences of postoperative adjustment difficulties and psychosocial change.

The second subgroup ($n = 11$, 29%) demonstrated a strong sense of self-change, either with or without engaging protective cognitive biases (narrative discrepancies). This subgroup was characterized as having *Embraced Change* through active self-reflection and reframing and appeared most closely aligned with an Achieved identity status.

Finally, a third small subgroup ($n = 4$, 10.5%) described an approach to meaning-making that reflected *Minimal Change*, characterized by a mild sense of change (usually a report of feeling somewhat more confident postsurgery) without a notable degree of self-reflection and reframing. This group appeared most closely aligned to a Diffused identity status.

3.3 | Benefits of embracing change postsurgery

We examined the relationships between the identified subgroups in Figure 3 and mood, HRQOL, and

TABLE 3 Relationship between Ego Identity Process Questionnaire identity status and approach to meaning-making

Approach to meaning-making	Diffused, n = 3	Foreclosed, n = 26	Moratorium, n = 7	Achieved, n = 2
Type, n (%)*				
Change	3 (100%)	9 (35%)	1 (14%)	2 (100%)
Continuity	0 (0%)	17 (65%)	6 (86%)	0 (0%)
Strength, n (%)				
Strong	1 (33%)	10 (38%)	2 (29%)	2 (100%)
Mild	2 (67%)	16 (62%)	5 (71%)	0 (0%)
Discrepancies, n (%)				
Discrepant	1 (33%)	12 (46%)	5 (71%)	1 (50%)
Consistent	2 (67%)	14 (54%)	2 (29%)	1 (50%)

Note: Approach to meaning-making was identified based on three key features (type, strength, and discrepancies) identified in patient narratives.

*p < .05.

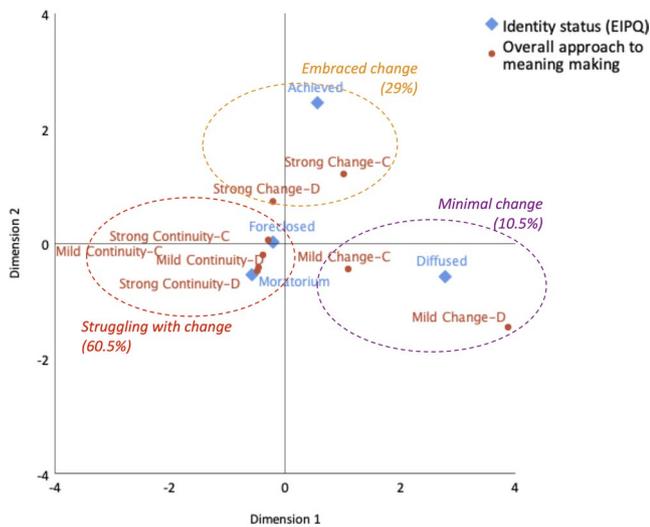


FIGURE 3 Correspondence analysis showing the relationships between patient approaches to meaning-making following surgery (narrative profiles in red) and identity status as measured by the Ego Identity Process Questionnaire (EIPQ in blue). The narrative profiles were coded according to the narrative type (change vs. continuity) and strength (strong vs. mild), and the presence of discrepancies (discrepant vs. consistent).¹ The combination of these features produced three theoretically cogent groups that aligned with the different identity statuses; those who had embraced change (*n* = 11, orange circle), those who were struggling with change (*n* = 23, red circle), and those who showed minimal change (*n* = 4). C, consistent narratives; D, discrepant narratives

clinical and demographic variables. One (OS) patient in the Embracing Change group was a significant outlier across the HRQOL and mood measures and hence was excluded from subsequent analyses (*n* = 37; see Figure S2 for the results with all 38 patients, showing a similar pattern). Patients in the Embracing Change group

reported significantly higher subjective cognitive functioning on the QOLIE-31 ($H[2] = 6.36, p = .041, \eta^2 = .13$, medium effect) compared to those in the Struggling With Change or Minimal Change groups, accompanied by a general trend toward higher HRQOL and mood outcomes (Figure 4).

Significant associations were also found for age at regular seizure onset ($H[2] = 6.6, p = .036, \eta^2 = .13$, medium effect) and duration of presurgical epilepsy ($H[2] = 7.8, p = .02, \eta^2 = .17$, large effect). In particular, patients who in the Embracing Change group were significantly younger at seizure onset (mean = 6.8 years, SD = 5.2) and had a longer duration of presurgical epilepsy (mean = 26.2 years, SD = 8.8), whereas those in the Struggling With Change group had the shortest duration of presurgical epilepsy (mean = 17.2, SD = 9.1) and were the oldest at regular seizure onset, with onset on average during adolescence (mean = 14.7, SD = 8.6).

4 | DISCUSSION

This is the first study to examine patient identity 15–20 years after ATL. Findings reflect some of the diversity in long-term postoperative adjustment trajectories and highlight a key role for patient identity in this process. A change in identity was evident in the post-ATL cohort relative to surgically naïve controls, with those 15–20 years postsurgery demonstrating a shift out of Diffused identity. Postoperative seizure outcome played an important role in identity change, with patients who experienced a better seizure outcome (either SF or MO) reporting less postoperative identity exploration at long-term follow-up.

By exploring the relationship between identity and meaning-making over the long term, we were able to

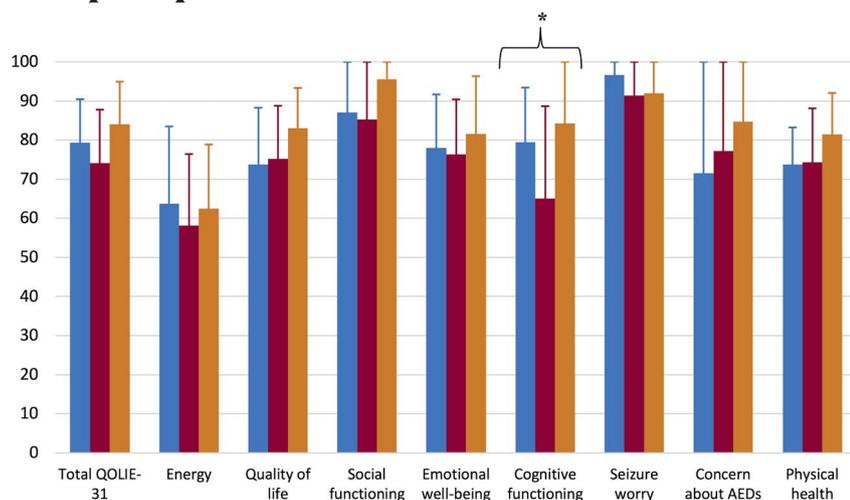
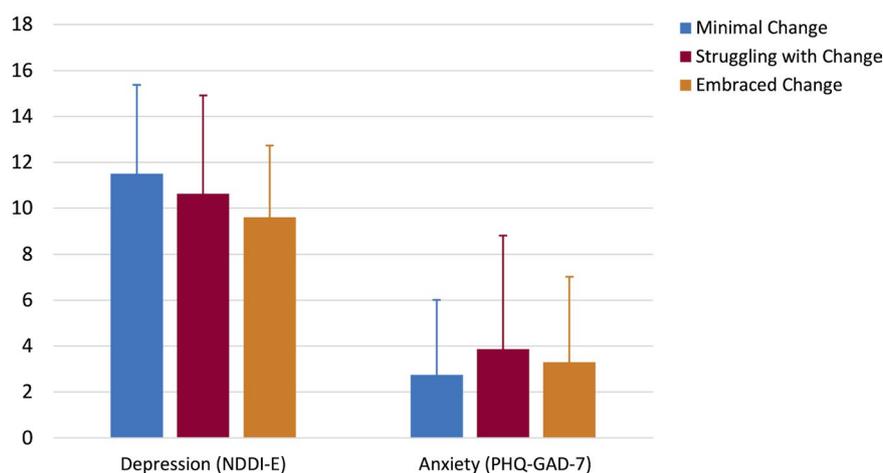


FIGURE 4 Self-reported health-related quality of life (HRQOL; top) and mood symptoms (bottom) according to the level at which patients embraced the postoperative meaning-making and self-reflection process. AEDs, antiepileptic drugs; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; PHQ-GAD-7, Patient Health Questionnaire for Generalized Anxiety Disorders-7-item; QOLIE-31, Quality of Life in Epilepsy Inventory-31-item. * $p < .05$



delineate three groups: (1) those who showed minimal engagement with this process of self-reflection and change, (2) those who had difficulty effectively engaging with this process, and (3) those who embraced this process postsurgery. The latter group was younger at epilepsy onset and had lived with epilepsy for longer prior to surgery, giving surgery greater potential to challenge their sense of self but also to prompt positive psychological growth.^{33,34}

4.1 | Indications of long-term postsurgical identity change

When compared to a surgically naïve epilepsy cohort,⁴ our ATL patients showed a shift out of Diffused identity. Interestingly, at long-term follow-up this change appeared to be underpinned by an increase in identity commitment, not exploration, with the majority of post-ATL patients in a Foreclosed status. Postoperative seizure status was significantly associated with identity, with 100% of the SF patients having Foreclosed identity status (reduced identity exploration). This was contrary to expectation, as

those who achieve seizure freedom are typically thought to engage more in the process of identity reconceptualization from chronically ill to well.^{14,15} Drawing on the qualitative literature, however, it may be that this shift to a Foreclosed identity reflects commitment to the presurgical expectation of achieving seizure freedom and/or feeling "cured" postsurgery, and the increased exploration of social opportunities described by some patients is circumscribed to the attempted fulfilment of presurgical expectations.^{14,16,35}

For example, common expectations include gaining a driver's license, increased vocational opportunities, and family milestones.³⁶⁻³⁸ The achievement of these milestones postsurgery may be more of an exercise of "catching up" with peers, rather than a true exploration of a diverse range of social and relational roles.^{19,39} Presurgical expectations may therefore limit the level of genuine exploration some patients are willing to engage with following surgery if seizures are eradicated. Further prospective and longitudinal analysis is needed to comprehensively characterize this process and examine whether patient expectations guide the degree of postoperative identity exploration and commitment.

The highest level of identity exploration was seen among patients experiencing more recent postsurgical seizure recurrence. Over the long term, the uncertainty of seizure recurrence may prompt increased questioning of the degree to which patients can engage with their desired social roles and values, now and into the future, as well as questioning whether they still have epilepsy. Of note, the two patients who had reached an Achieved identity status at long-term follow-up both experienced ongoing seizures following surgery. This may represent the successful resolution of this questioning process, and acceptance of epilepsy as part of their identity. The broader meaning-making literature suggests that those who are able to view uncertainty as an opportunity for change are best placed to engage with the meaning-making process.⁴⁰

Patients appeared to demonstrate subjective insight into their identity status given its association with narrative type; in other words, identity status as measured by the EIPQ was significantly associated with self-report of being a different person postsurgery (or not). This finding aligns with theories of meaning-making that suggest identity development and maturity may be considered "outcomes" of the meaning-making process.³³ In contrast, there was no association between identity status and narrative strength or the presence of discrepancies, suggesting that although these aspects of meaning-making aid identity development postsurgery, meaning-making and identity development are not synonymous constructs. This is also consistent with the broader meaning-making literature, which suggests identity change can be an outcome of the meaning-making process.^{33,41,42}

4.2 | Positive psychological growth and the benefits of embracing change

Our findings also illustrated the value of meaning-making as a tool to facilitate postoperative identity development, as it allows for the incorporation of key experiences and emotional learning into one's sense of self.^{33,41,42} Here, we identified three subgroups varying in the degree to which they embraced the process of meaning-making and identity change following surgery, with approximately one third embracing change.

The successful engagement in meaning-making that results in improved well-being and a positive sense of self is typically referred to as posttraumatic growth.^{33,43} A major challenge to an individual's sense of self is thought to be key to prompting posttraumatic growth.^{33,43} In line with this, those who had embraced change had a younger age at regular seizure onset and longer duration of presurgery

epilepsy. Patients who have been living with epilepsy for longer appear more likely to see surgery as a major challenge to their sense of self, particularly if epilepsy emerged prior to the key stage of identity development in adolescence. Consistent with this, short-term research has also identified greater experiences of the burden of normality as well as greater perceived postoperative personality change among patients with younger age of regular seizure onset.⁴⁴

Those in Foreclosed and Moratorium appeared to have difficulties effectively engaging with the meaning-making process. This may initially appear counterintuitive, given that they represent opposing identity profiles of low commitment, high exploration (Moratorium) and high commitment, low exploration (Foreclosed). However, these groups may be "struggling with change" in different ways. As noted earlier, patients with a Foreclosed identity status were more likely to have maintained seizure freedom over the longer term, potentially allowing the avoidance of self-reflection and meaning-making to remain unchallenged due to the absence of seizure recurrence. The fulfilment of their presurgical expectations may be the extent to which they engage with psychosocial change and adjustment, precluding a deeper meaning-making or benefit-finding process.

Consistent with the idea of "struggling with change," the broader identity literature notes that the high self-exploration evident in Moratorium is primarily an information-seeking process that can generate feelings of both distress and exhilaration, and low commitment can prompt a negative affect due to a yearning for a stronger personal identity.^{1,2,23,45}

4.3 | Clinical implications

Our findings point toward the psychologically adaptive benefits of embracing a process of self-reflection. More broadly, using meaning-making to create cohesive, well-structured narratives has been found to help patients make sense of traumatic events and promote greater well-being.^{33,43} Active therapeutic approaches such as narrative therapy may be particularly useful for supporting this process, with cognitive reframing shown to be successful for poststroke patients who experience a loss of self.⁴⁶

Acceptance and commitment therapy (ACT) has also shown significant benefits in promoting posttraumatic growth among long-term cancer survivors following diagnosis and treatment.⁴⁷ Although ACT has been utilized to improve general mood and self-management among people living with epilepsy,^{48,49} as well as those with nonepileptic seizures,⁵⁰ it has not specifically been utilized to support patients through postsurgical adjustment.

4.4 | Study limitations

The process of shedding the sick role following epilepsy surgery has been identified through qualitative research as a key aspect of postsurgical identity reconceptualization.^{14,16} The EIPQ, however, does not include questions on health and/or chronic illness as a part of identity.²² As such, it may not capture the full breadth of patient identity exploration following epilepsy surgery.

Although our sample was robust for the original qualitative analysis,^{17,19} the small sample size represents a challenge for secondary quantitative analysis. For example, our original qualitative work noted that most discrepant narratives captured a more positive trajectory than documented, but a few were the reverse (i.e., patients reporting a more negative adjustment trajectory than that documented in psychosocial records). Numbers were too small, however, to analyze any further subgroups than the ones included here.

There was a significant difference in age at onset of epilepsy between the surgical and surgically naïve groups, with the surgical group having younger age of habitual seizure onset. Theoretically, this may suggest that the surgical group experienced greater identity disruption prior to surgery, making the postoperative change potentially even more distinct. This cannot be determined, however, without a longitudinal study that tracks identity change pre- to postsurgery. The current paper is therefore considered an early descriptive study, providing greater theoretical depth to our understanding of long-term postsurgical psychosocial adjustment, and highlighting avenues for further empirical research.

4.5 | Future directions

Our paper stands as an initial exploration of identity in a group of patients who underwent ATL. Further work is needed to disentangle other factors contributing to identity development and change among patients with epilepsy. One valuable avenue for further study would be to explore the impact of full-scale intelligence quotient (FSIQ) and language function on narrative measures. Due to our inclusion criteria, there was not significant variation in FSIQ in the current study to explore the possible impact of intellectual function on narrative expression. The psychosocial outcomes of surgery for patients with an intellectual disability (ID) is an understudied area, including the impact of ID on identity change and development. With regard to language function, previous research has shown that people with TLE produce increasingly verbose accounts of stories on successive retellings, in contrast to healthy controls who produce increasingly concise stories.⁵¹ The relationship between epilepsy, language, and identity may therefore be a complex one, worth exploring further in its own study.

Future research is also needed to examine broader psychosocial factors that may influence the meaning-making process among patients with epilepsy, such as psychiatric history, personality, and/or social support. Interestingly, the meaning-making groups identified in our study were broadly consistent with different adjustment trajectories seen following natural disaster.⁵² More specifically, the change-related groups identified here (Minimal Change, Struggling With Change, and Embracing Change) resemble those of Davis et al., who examined family responses to the loss of a loved one in the 1992 Westray mine collapse in Canada. Davis et al. described three groups: (1) those who showed a typical pattern of posttraumatic growth, (2) those who perceived minimal threat to their sense of self and therefore showed minimal engagement with meaning-making, and (3) those who did not experience growth because they could not identify meaning in the situation.⁵² Taken with the findings from our current study, this may point to natural variation in individual adjustment trajectories following adversity and highlights the importance of exploring intrapersonal factors as well as seizure variables in future work.

5 | CONCLUSIONS

This was the first study to comprehensively examine patient self-identity at long-term (15–20 years) postsurgical follow-up and delineate the complex relationship between patient identity, seizure outcome, and well-being. Of particular importance for clinicians, our findings point to the lasting benefits of embracing the process of self-change and meaning-making for long-term patient well-being. Findings also highlight the unique opportunity to study meaning-making and posttraumatic growth afforded by epilepsy surgery, given that the majority of this literature explores such change following objectively negative life events, whereas epilepsy surgery is generally considered a positive step in a patient's life.

ACKNOWLEDGMENTS

We thank Prof. Terence O'Brien for his support of the larger project of which this study is a part; Prof. Sam Berkovic and Dr. Marie O'Shea from the Melbourne Brain Centre, Austin Health for their input and support with recruitment and data collection; Kिररily Rogers for her thoughtful and insightful discussion on qualitative and patient-centered research; and James Allebone for his work on understanding identity in the preoperative cohort and for his assistance in facilitating a pre- to postoperative comparison that sheds further light on the impact of epilepsy and its treatment on identity.

H.C. was the recipient of an Australian Postgraduate Award during her PhD candidacy.

CONFLICT OF INTEREST

None of the authors has any conflict of interest to disclose. 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.

ORCID

Honor Coleman  <https://orcid.org/0000-0002-5532-9327>

Anne McIntosh  <https://orcid.org/0000-0002-5020-260X>

Genevieve Rayner  <https://orcid.org/0000-0002-0747-3877>

Sarah J. Wilson  <https://orcid.org/0000-0002-2678-1576>

REFERENCES

- Erikson EH. Identity and the life cycle: selected papers. Oxford, UK: International Universities Press; 1959.
- Kroger J. Identity development. Thousand Oaks, CA: SAGE Publications; 2006.
- Wilson SJ, Wrench JM, McIntosh AM, Bladin PF, Berkovic SF. Personality development in the context of intractable epilepsy. *Arch Neurol*. 2009;66(1):68–72.
- Allebone J, Rayner G, Siveges B, Wilson SJ. Altered self-identity and autobiographical memory in epilepsy. *Epilepsia*. 2015;56(12):1982–91.
- 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(1):15–31.
- Scott AJ, Sharpe L, Thayer Z, Miller LA, Wong T, Parratt K, et al. A qualitative examination and theoretical model of anxiety in adults with epilepsy. *Epilepsy Behav*. 2018;85:95–104.
- Collard SS, Marlow C. “It’s such a vicious cycle”: narrative accounts of the sportsperson with epilepsy. *Psychol Sport Exerc*. 2016;24:56–64.
- Nanton V, Munday D, Dale J, Mason B, Kendall M, Murray S. The threatened self: considerations of time, place, and uncertainty in advanced illness. *Br J Health Psychol*. 2016;21(2):351–73.
- Bora E, Meletti S. Social cognition in temporal lobe epilepsy: a systematic review and meta-analysis. *Epilepsy Behav*. 2016;60:50–7.
- Richard AE, Scheffer IE, Wilson SJ. Features of the broader autism phenotype in people with epilepsy support shared mechanisms between epilepsy and autism spectrum disorder. *Neurosci Biobehav Rev*. 2017;75:203–33.
- 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(5–6):627–50.
- Gracey F, Evans JJ, Malley D. Capturing process and outcome in complex rehabilitation interventions: a “Y-shaped” model. *Neuropsychol Rehabil*. 2009;19(6):867–90.
- Whiffin CJ, Ellis-Hill C, Bailey C, Jarrett N, Hutchinson PJ. We are not the same people we used to be: an exploration of family biographical narratives and identity change following traumatic brain injury. *Neuropsychol Rehabil*. 2017;29(8):1256–72.
- Bladin PF. Psychosocial difficulties and outcome after temporal lobectomy. *Epilepsia*. 1992;33(5):898–907.
- Wilson SJ, Bladin PF, Saling MM. Paradoxical results in the cure of chronic illness: the “burden of normality” as exemplified following seizure surgery. *Epilepsy Behav*. 2004;5(1):13–21.
- Wilson S, Bladin P, Saling M. The, “burden of normality”: concepts of adjustment after surgery for seizures. *J Neurol Neurosurg Psychiatry*. 2001;70(5):649–56.
- Coleman H, McIntosh A, Wilson SJ. A patient-centered approach to understanding long-term psychosocial adjustment and meaning-making, 15 to 20 years after epilepsy surgery. *Epilepsy Behav*. 2020;102:e106656.
- Hamiwka L, MacRodimitris S, Tellez-Zenteno JF, Metcalfe A, Wiebe S, Kwon CS, et al. Social outcomes after temporal or extratemporal epilepsy surgery: a systematic review. *Epilepsia*. 2011;52(5):870–9.
- Coleman H, McIntosh A, Wilson SJ. Identifying the trajectory of social milestones 15–20 years after epilepsy surgery: realistic timelines for postsurgical expectations. *Epilepsia Open*. 2019;4(3):369–81.
- 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.
- 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.
- Balistreri E, Busch-Rossnagel NA, Geisinger KF. Development and preliminary validation of the Ego Identity Process Questionnaire. *J Adolesc*. 1995;18:179–92.
- Marcia JE. Development and validation of ego-identity status. *J Pers Soc Psychol*. 1966;3:551–8.
- Schwartz SJ. Construct validity of two identity status measures: the EIPQ and the EOM-EIS-II. *J Adolesc*. 2004;27:477–83.
- Mula M, McGonigal A, Micoulaud-Franchi J-A, May TW, Labudda K, Brandt C. Validation of rapid suicidality screening in epilepsy using the NDDIE. *Epilepsia*. 2016;57:949–55.
- Gilliam FG, Barry JJ, Hermann BP, Meador KJ, Vahle V, Kanner AM. Rapid detection of major depression in epilepsy: a multi-centre study. *Lancet Neurol*. 2006;5:399–405.
- Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. *Arch Intern Med*. 2006;166(10):1092–7.
- Vickrey BG, Perrine KR, Hays RD, Hermann BP. Quality of Life in Epilepsy, QOLIE-31, scoring manual version 1.0. Santa Monica, CA: RAND; 1993.
- Cramer JA, Perrine K, Devinsky O, Bryant-Comstock L, Meador K, Hermann B. Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia*. 1998;39:81–8.
- Rosenthal R. Parametric measures of effect size. In: Cooper H, Hedges LV, editors. *The handbook of research synthesis*. New York, NY: Russell Sage Foundation; 1994. p. 231–44.
- Doey L, Kurta J. Correspondence analysis applied to psychological research. *Tutor Quant Methods Psychol*. 2011;7(1):5–14.
- Greenacre MJ, Blasius J. Correspondence analysis in the social sciences. Oxford, UK: Academic Press; 1994.
- 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.

34. 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.
35. Elliott IM, Lach L, Lou SM. Adolescent and maternal perspectives of quality of life and neuropsychological status following epilepsy surgery. *Epilepsy Behav*. 2000;1(6):406–17.
36. Taylor DC, McMackin D, Staunton H, Delanty N, Phillips J. Patients' aims for epilepsy surgery: desires beyond seizure freedom. *Epilepsia*. 2001;42:629–33.
37. Wheelock I, Peterson C, Buchtel HA. Presurgery expectations, postsurgery satisfaction, and psychosocial adjustment after epilepsy surgery. *Epilepsia*. 1998;39(5):487–94.
38. Ozanne A, Graneheim UH, Ekstedt G, Malmgren K. Patients' expectations and experiences of epilepsy surgery—a population-based long-term qualitative study. *Epilepsia*. 2016;57(4):605–11.
39. Côté JE, Levine C. A critical examination of the identity status paradigm. *Dev Rev*. 1988;8:147–84.
40. Dauphin S, Van Wolputte S, Jansen L, De Burghgraeve T, Buntinx F, van den Akker M. Using liminality and subjunctivity to better understand how patients with cancer experience uncertainty throughout their illness trajectory. *Qual Health Res*. 2020;30:356–65.
41. McLean KC. Late adolescent identity development: narrative meaning making and memory telling. *Dev Psychol*. 2005;41(4):683–91.
42. McLean KC, Pratt MW. Life's little (and big) lessons: identity statuses and meaning-making in the turning point narratives of emerging adults. *Dev Psychol*. 2006;42(4):714–22.
43. Calhoun LG, Tedeschi RG. *Posttraumatic growth in clinical practice*. New York, NY: Routledge; 2012.
44. Wilson SJ, Wrench JM, McIntosh AM, Bladin PF, Berkovic SF. Profiles of psychosocial outcome after epilepsy surgery: the role of personality. *Epilepsia*. 2010;51:1133–8.
45. Meeus W, Iedema J, Helsen M, Vollebergh W. Patterns of adolescent identity development: review of literature and longitudinal analysis. *Dev Rev*. 1999;19:419–61.
46. Chow EOW. Narrative therapy an evaluated intervention to improve stroke survivors' social and emotional adaptation. *Clin Rehabil*. 2015;29:315–26.
47. Fernández-Rodríguez C, González-Fernández S, Coto-Lesmes R, Pedrosa I. Behavioral activation and acceptance and commitment therapy in the treatment of anxiety and depression in cancer survivors: a randomized clinical trial. *Behav Modif*. 2020;21:e0145445520916441.
48. Dewhurst E, Novakova B, Reuber M. A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy. *Epilepsy Behav*. 2015;46:234–41.
49. Lundgren T, Dahl JA, Hayes SC. Evaluation of mediators of change in the treatment of epilepsy with acceptance and commitment therapy. *J Behav Med*. 2008;31:225–35.
50. Cope SR, Poole N, Agrawal N. Treating functional non-epileptic attacks—should we consider acceptance and commitment therapy? *Epilepsy Behav*. 2017;73:197–203.
51. Field SJ, Saling MM, Berkovic SF. Interictal discourse production in temporal lobe epilepsy. *Brain Lang*. 2000;74:213–22.
52. Davis CG, Wohl MJA, Verberg N. Profiles of posttraumatic growth following an unjust loss. *Death Stud*. 2007;31:693–712.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Coleman H, McIntosh A, Rayner G, Wilson SJ. Understanding long-term changes in patient identity 15–20 years after surgery for temporal lobe epilepsy. *Epilepsia*. 2021;00:1–12. <https://doi.org/10.1111/epi.17027>