

RESEARCH ARTICLE

“Do I still have epilepsy?” Epilepsy identity 15–20 years after anterior temporal lobectomy

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

¹Melbourne School of Psychological Sciences, The University of Melbourne, Melbourne, Vic., Australia

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

³Melbourne Brain Centre, Department of Medicine, The Royal Melbourne Hospital, University of Melbourne, Melbourne, Vic., Australia

Correspondence

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

Abstract

Objective: Identity is a multifaceted construct, comprising personal identity (sense of being a unique individual) and social identity (the sense-of-self derived from membership of social groups). Social identity involves explicit identification with a group (“I am ...”) and implicit behaviors or attitudes associated with group membership. Following successful treatment with surgery, patients with epilepsy can undergo a complex and lasting change in personal identity. To date, there has been no research into postoperative social epilepsy identity (SEI). We sought to examine SEI 15–20 years post-surgery, and the relationship between SEI and satisfaction with surgery, psychosocial improvements, mood, and health-related quality of life (HRQoL).

Methods: Thirty-two patients who underwent anterior temporal lobectomy (ATL; 19 female) were recruited, with a median follow-up of 18 years (interquartile range [IQR] = 2.5). Using a novel interactive online program, we collected data on SEI, satisfaction with surgery, and perceived psychosocial improvements, alongside standardized measures of mood (Neurological Disorders Depression Inventory-Epilepsy; Patient Health Questionnaire-Generalised Anxiety Disorder-7 item) and HRQoL (Quality of Life in Epilepsy-31 item). Non-parametric analyses were used to analyse the data.

Results: Twenty-five percent of patients were free of disabling seizures since surgery, yet 65% stated they no longer had epilepsy and >90% reported satisfaction with surgery. Explicitly discarding SEI was positively associated with HRQoL at long-term follow-up, over and above seizure outcome. Implicit SEI was expressed as (a) acceptance of epilepsy, (b) a sense of belonging to the epilepsy community, and (c) difficulty disclosing and discussing epilepsy. Difficulty disclosing and discussing epilepsy was associated with increased anxiety and lower HRQoL.

Significance: At long-term follow-up, over half of our patients reported an explicit change in SEI, which could promote better HRQoL. In contrast, difficulty with disclosure of epilepsy was associated with increased anxiety and reduced HRQoL, possibly reflecting the ongoing effects of stigma. These findings highlight the importance of understanding changes in patient social identity for promoting long-term well-being after surgery.

KEYWORDS

epilepsy surgery, health-related quality of life, long-term follow-up, online data collection, social identity

1 | INTRODUCTION

Chronic epilepsy has been found to influence identity development through both psychosocial and neurobiological mechanisms, leading to integration of the diagnosis into an individual's sense of self.^{1–3} This research has focused predominantly on personal identity, or the development of a unique sense of self that is informed by personal experiences, memories, and values. There has been less research specifically examining social identity in epilepsy, or the self-concept derived from membership of a social group and the value and emotional significance attached to this membership.^{4,5}

Surgery is a well-established and effective treatment option for patients with drug-resistant epilepsy. Although surgery has been found to result in better seizure control and improved health-related quality of life (HRQoL) compared to treatment with ongoing medication,^{6–14} a sudden reduction in seizure frequency can paradoxically trigger complex adjustment issues for patients as they learn to “shed” epilepsy from their identity.^{15,16} This process, termed the burden of normality, manifests as a range of symptoms across psychological, sociological, behavioral, and affective domains, and can result in significant distress for patients and their families.^{14–18} There has been relatively less focus on patient identity over the longer term (>5–10 year follow-up).^{19,20} Recent research from our group exploring very long-term (>15 year) post-surgical psychosocial trajectories, however, highlighted a lasting impact of surgery on personal identity.^{21,22}

Complementary to personal identity, social identity is a multi-dimensional construct, which considers both the individual's self-identification with particular roles or groups as well as attitudes and behaviors toward said groups.⁴ Self-identification with a group is considered an explicit measure of identity, that is, explicitly stating “I am someone with epilepsy.” Another facet of social identity that we can measure relates to a person's implicit attitudes and behaviors associated with group membership, such as joining peer support groups, participating in research, or advocating for supports and services for people with epilepsy.^{4,5,23}

To date, research on social identity in epilepsy has focused predominantly on the experience of stigma for people living with epilepsy and how this may vary across different cultures.^{1,24} There is a dearth of research examining the nuances of social identity in people living

Key points

- Fifteen to 20 years after epilepsy surgery, 65% of patients had explicitly discarded their social epilepsy identity (SEI).
- More than 90% of patients were satisfied with surgery despite complete seizure freedom in only 25%.
- Explicitly discarding SEI reflected a sense of being “cured” post-surgery.
- Explicitly discarding SEI was positively associated with health-related quality of life (HRQoL) long term and mediated the relationship between seizure outcome and HRQoL.
- Implicitly maintaining SEI, reflected by difficulties with disclosure or discussion, was associated with increased anxiety and poorer HRQoL.

with epilepsy, and to date no research into the long-term impact of surgery on social identity. The current study therefore set out to examine social epilepsy identity (SEI), 15–20 years following surgery for temporal lobe epilepsy (TLE). Through the process of personal identity reconceptualization following surgery,¹⁶ do patients “shed” the social identity or sense of being a person with epilepsy? Furthermore, is this associated with implicit changes in attitudes associated with the change in social identity?

Typically, studies examining identity in epilepsy have utilized in-depth qualitative interviews or focus groups.^{22,25–27} However, conducting interviews is a time-consuming process, which, when combined with barriers to attending face-to-face interviews, can result in loss of postoperative follow-up. A secondary aim of the current study was therefore to test an interactive online method of collecting psychosocial outcome data, including nuanced exploration of issues relating to identity, developed by our research team (the “Living with Epilepsy” program).²⁸

Utilizing data collected from the Living with Epilepsy program, both explicit and implicit measures of epilepsy identity were examined according to the following hypotheses: (1) explicit identification as someone with epilepsy would be associated with implicit attitudes reflecting participation in the epilepsy community; (2) no longer identifying as someone with epilepsy would be associated with (a) better seizure outcome, and greater (b)

satisfaction with surgery, (c) self-reported improvements in psychosocial outcomes, and (d) mood and HRQoL at long-term follow-up.

2 | METHOD

The current study is a cross-sectional quantitative examination of social identity, 15–20 years post-surgery.

2.1 | Participants

This study was approved by the human research ethics committee of Austin Health and The University of Melbourne, Australia. All patients gave informed consent in accordance with the Declaration of Helsinki. Inclusion criteria were: (a) a single documented anterior temporal lobectomy (ATL) for drug-resistant TLE, (b) age ≥ 18 years at the time of surgery. Exclusion criteria were (a) significantly reduced intellectual capacity, and/or (b) poor English language that would have precluded ability to engage in a lengthy psychosocial interview and set of self-report questionnaires. Diagnosis and surgical suitability was confirmed at the time of admission to the Austin Health Comprehensive Epilepsy Program (CEP) according to established methods, including clinical, video electroencephalography (EEG), neuropsychological, psychiatric, and neuroimaging investigations.^{29–31}

Post-surgery, all patients underwent routine medical and psychosocial follow-up for 24 months,^{14,30,31} after which they typically received second yearly follow-up by telephone if there had been no contact with the CEP during this time. Follow-up information was documented relating to their progress, including seizure outcome. Given the dynamic nature of seizure outcomes over time, classifying post-surgical seizure status for research purposes can be difficult and can affect the reporting of psychosocial benefits and/or quality of life outcomes after surgery. We have adopted an approach similar to Sperling et al.,³² who grouped patients into those who were seizure-free, those with a mixed outcome comprising some years of seizure freedom and some years with seizures, and those with persisting seizures. For our cohort, seizure outcome was classified as the following: (a) seizure-free (SF), with or without auras; (b) mixed outcome (MO), those with one or more periods of seizure freedom ≥ 5 years; or (c) ongoing seizures (OS), those with no period of seizure freedom ≥ 5 years.

The recruitment process for the current study has been described previously.^{21,22} Briefly, 41 patients (24 female; 26 left-sided) who underwent ATL between

1994 and 2002 with a median follow-up of 18.4 years (IQR = 4.7) participated in a larger study.^{21,22} Of these, 32 completed the *Living with Epilepsy* program, which included measures of SEI (Table 1). Compared to those who did not complete the program ($n = 9$), the final sample ($n = 32$) was significantly younger at the time of participation ($U = 55$, $p < .01$, $r = -.43$) and at surgery ($U = 76.5$, $p = .03$, $r = -.34$), and was more likely to have completed education above a secondary school level, ($X^2(3) = 8.96$, $p = .03$).

2.2 | Materials

2.2.1 | Living with epilepsy: measuring identity, satisfaction, and psychosocial improvements

The *Living with Epilepsy* program takes ~30 min to complete and contains three main sections that explore the impact of epilepsy on (a) identity, (b) satisfaction and regret with surgery and perceived psychosocial improvements, as well as (c) psychosocial activities and family dynamics. Issues targeted in the program are based on previous qualitative research by our group,^{14,16} and informed by the broader psychological literature on both personal and social identity.^{4,33–35} The program utilizes a mix of data collection techniques, including rating scales, graphical representations, and free-answer textboxes that flexibly prompt for individual patient experiences in a sensitive way.

Of particular relevance to this study, Section I (“Myself and My Epilepsy”) includes an assessment of implicit SEI using 12 statements adapted from a well-established measure of ethnic identity.⁴ For each statement, patients were asked to rate different attitudes toward epilepsy (from 0 = *Untrue of me* to 4 = *Very true of me*). Examples of statements include “I feel good about my epilepsy” and “I feel uncomfortable around others who have epilepsy.”

Two further statements examine explicit SEI following surgery, namely “I believe the operation has cured my epilepsy” and “I no longer feel that I have epilepsy.” Patients are then asked the explicit, forced-choice question “Do you still have epilepsy?” (Yes/No).

The *Living with Epilepsy* program also captures information on satisfaction by asking patients if they (a) felt surgery was a success, (b) were satisfied with life after surgery, and/or (c) regretted having surgery. Finally, patients were asked to rate perceived improvements across several psychosocial domains, including self-confidence, personality, memory, employment, and family dynamics on a scale of 1 to 100%. Further information can be found in Table S1.

TABLE 1 Clinical demographics for patients included in the final analysis

	n (%) or mean (SD)
Gender (female)	19 (59%)
Laterality (left)	20 (63%)
Residency	
Victoria, Australia	14 (44%)
Interstate, Australia	15 (47%)
Overseas (NZ)	3 (9%)
Presence of GTCS pre-surgery (yes)	11 (34%)
Mean current age (SD)	49.3 years (6.9)
Mean age at surgery (SD)	31.3 years (8.2)
Median age at onset (IQR)	8.8 years (13.5)
Median duration of epilepsy (IQR)	20.1 years (13.1)
Median length of follow-up (IQR)	18.1 years (4.9)
Median time since last seizure (IQR)	14.7 years (16.0)
Seizure outcome	
Seizure-free	8 (25%)
Mixed outcome	19 (59%)
Ongoing seizures	5 (16%)
Medication regimen at follow-up	
No AEDs	6 (19%)
Monotherapy	19 (59%)
Polytherapy	7 (22%)
Currently driving (yes)	27 (84%)
Highest level of education	
Secondary school	16 (50%)
TAFE	6 (19%)
University	10 (31%)
Current level of employment	
Full-time	17 (53%)
Part-time	2 (6%)
Unemployed	11 (34%)
Retired	2 (6%)

n = 32.

Abbreviations: AEDs, anti-epileptic drugs; GTCS, generalized tonic-clonic seizures; IQR, interquartile range; NZ, New Zealand; SD, standard deviation; TAFE, Technical and Further Education.

2.2.2 | Mood and HRQoL

The Neurological Disorders Depression Inventory-Epilepsy (NDDI-E) is a self-report measure of depressive symptoms that do not overlap with commonly comorbid cognitive difficulties associated with epilepsy or the adverse effects of antiseizure medications (ASMs). It has been well validated and used extensively in epilepsy research.³⁶ The Patient Health Questionnaire for

Generalized Anxiety Disorder-7-item (PHQ-GAD-7) was used to assess anxiety symptoms. It has been validated in general medical populations and shows good sensitivity and specificity for mild, moderate, and severe anxiety.³⁷

Finally, the Quality of Life in Epilepsy Scale-31 Items (QOLIE-31) was used to assess HRQoL.^{38,39} Subscales focus on the emotional and psychological effects of epilepsy (seizure worry, cognitive function, emotional well-being, energy/fatigue) and its medical and social effects (effects of medication, work, driving, social restrictions). Studies demonstrate good internal consistency and test-retest reliability.^{38,39} Higher scores reflect better subjective HRQoL.

2.3 | Data analysis

All analyses were conducted using IBM SPSS Statistics, version 24. All tests were two-tailed and a 5% significance level was used throughout. Due to the small sample size and non-normal distribution of the data, nonparametric tests were used to examine between-group differences, namely Mann-Whitney *U*, Pearson correlation, and chi-square.⁴⁰

To test hypothesis 1, that explicit SEI would be associated with implicit attitudes toward epilepsy, we first extracted factors representing explicit and implicit SEI.

Explicit SEI was assessed in two ways: (a) patients were grouped according to their response to the question “Do you still have epilepsy?” and (b) principal components analysis (PCA) was used to combine the two scale items examining explicit SEI (“I believe the operation has cured my epilepsy” and “I no longer feel that I have epilepsy”) into a single factor. Varimax rotation was used to simplify the internal structure of the data by maximizing the variance of the loadings within factors.⁴⁰ As expected, both statements loaded strongly onto a single component (both at 0.95), explaining 91% of the variance in the data. This factor was saved as a continuous measure of explicit SEI following surgery.

For implicit SEI, we used PCA to identify underlying factors for the 12 statements assessing implicit attitudes toward epilepsy. Bartlett’s test of sphericity indicated that correlations between statements were sufficiently large for PCA ($\chi^2(66) = 146.84, p < .001$) and the Kaiser-Meyer-Olkin measure revealed sampling to be adequate (KMO = 0.58). Correlations were run to assess the associations between the resulting principal components representing the explicit and implicit measures of SEI.

Hypothesis 2 sought to determine whether SEI was associated with clinical, mood, and HRQoL outcomes at long-term follow-up. To this end, between-group comparisons were conducted on the principal components

representing explicit and implicit SEI for seizure outcome (SF vs MO vs OS), and reported satisfaction and regret with surgery (Yes vs No). Correlations were run for patient-perceived psychosocial improvements and scores on the NDDI-E, PHQ-GAD-7, and QOLIE-31.

3 | RESULTS

3.1 | Explicit SEI

Based on the question “Do you still have epilepsy?” approximately one third of patients ($n = 11$, 35%) explicitly identified as someone who still has epilepsy, whereas two thirds ($n = 21$, 65%) stated they no longer have epilepsy. The latter group ($n = 21$) included all patients who were SF ($n = 10$), as well as 11 (58%) of the MO patients and none of the OS patients.

3.2 | Implicit SEI

The PCA of the 12 statements revealed four principal components based on eigenvalues over Kaiser's criterion of 1 and examination of the scree plot, accounting for 73% of the variance in the data. Inspection of the final four components, however, revealed that one component included only a single statement (“I have a strong sense of being a person with epilepsy”) (Table S2). Given that this statement did not align with implicit perceptions and was negatively associated with the explicit statements, it was removed and the analysis was re-run. From the remaining 11 statements, 3 principal components were identified based on eigenvalues over Kaiser's criterion of 1 and examination of the scree plot (Figure S1), accounting for 66% of the variance in the data.

Table 2 shows the final three component loadings after varimax rotation. Three statements loaded on the first component, which reflected a positive understanding and acceptance of the role of epilepsy in patient lives (“Acceptance of epilepsy”). Component 2 included four statements reflecting a desire to participate in activities with other people with epilepsy and for the benefit of people with epilepsy (“Belonging to the epilepsy community”). Finally, four statements loaded onto component 3, reflecting patient ease around others with epilepsy and attempts to learn more about their own epilepsy (“Discussion and disclosure”). These components were saved as continuous variables for further analysis.

Of note, two statements (“I feel uncomfortable around others with epilepsy” and “I mostly spend time with other

people who have epilepsy”) showed low response variation (Figure 1). To ensure this was not affecting the final component solution, the PCA was re-run without these statements. Because the same three-component solution emerged, the initial solution was kept, allowing for more nuance in the data (Table S2 and Table 2).

3.3 | Relationship between explicit and implicit SEI

Patients were grouped according to their response to the question “Do you still have epilepsy?” Contrary to our first hypothesis, no significant difference was found between the groups on the measures of implicit SEI. As can be seen in Figure 1, however, those who felt they still have epilepsy demonstrated a trend toward a greater sense of belonging to the epilepsy community and greater difficulties discussing and disclosing their epilepsy.

As would be expected, there was a significant correlation between the dichotomous measure of explicit SEI (“Do you still have epilepsy?”) and the continuous measure of SEI obtained through PCA ($U = 12$, $p = .000$, $r = -.14$). The continuous measure of explicit SEI, reflecting a sense of cure following surgery, was therefore used for the remainder of the study to allow for more nuanced analysis.

Table 3 shows the correlations between explicit and implicit SEI. Consistent with the finding for the dichotomous measure, no significant correlations were found.

3.4 | Explicit SEI, clinical and demographic factors

In line with hypothesis 2, explicit SEI showed a significant association with postsurgical seizure outcome ($H(2) = 9.3$, $p = .010$) and post-surgical AED use ($H(2) = 11.3$, $p = .003$). A greater sense of being a person *without* epilepsy was seen among those who were SF > MO > OS and those who were off ASMs > monotherapy > polytherapy. A significant correlation was also found between time since most recent seizure and explicit SEI ($r(28) = .55$, $p = .002$).

For implicit SEI, a positive correlation was found only between time since most recent seizure and acceptance of epilepsy ($r(28) = .54$, $p = .002$). Greater acceptance of epilepsy was also found among women ($U = 52$, $p = .027$, $r = -.08$) and those patients who did not experience generalized tonic-clonic seizures (GTCS) prior to surgery ($H(1) = 4.0$, $p = .045$).

TABLE 2 Results of the principal component analysis, showing the factor loadings for the three components reflecting patient implicit perceptions of epilepsy

	Resulting principal components		
	1 Acceptance of epilepsy	2 Belonging to the epilepsy community	3 Discussion and disclosure
I feel good about my epilepsy	.833		
I understand what my epilepsy means in my life	.909		
I have a clear sense of my epilepsy and what it means for me	.930		
I participate in activities that support the needs of people with epilepsy		.697	
I tend to judge people by their attitudes toward my epilepsy		.864	
I mostly spend time with other people who have epilepsy		.898	
I am strongly attached to my epilepsy		.400	
I think a lot about how my life will be affected by my epilepsy	.390		.472
In order to learn more about my epilepsy, I have often talked to others about it			.760
I feel uncomfortable around others who have epilepsy	.314		-.769
I spend time trying to find out about my epilepsy			.793

3.5 | High levels of satisfaction with surgery

Thirty patients responded to questions regarding satisfaction with surgery. No patient regretted the decision to undergo surgery. Two (6.7%) reported that they were not satisfied with surgery, and of these, one (3.3%) also reported that her surgery had not been a success due to psychiatric difficulties. Both of these patients were in the OS group. Given the overall high levels of satisfaction with surgery (93.3%), the association with SEI could not be reliably examined due to ceiling effects.

3.6 | The psychosocial and HRQoL benefits of explicitly discarding the SEI

Explicit SEI was significantly correlated with several patient-perceived benefits following surgery, including cessation of seizures and reduced medication load, as well as the ability to drive and a greater sense of independence (Table 3). A greater sense of being someone *without* epilepsy was also significantly correlated with higher total scores on the QOLIE-31 as well as the QOLIE-31 subscales of quality of life, social functioning, seizure worry, and concern about the effects of medication (Table 3).

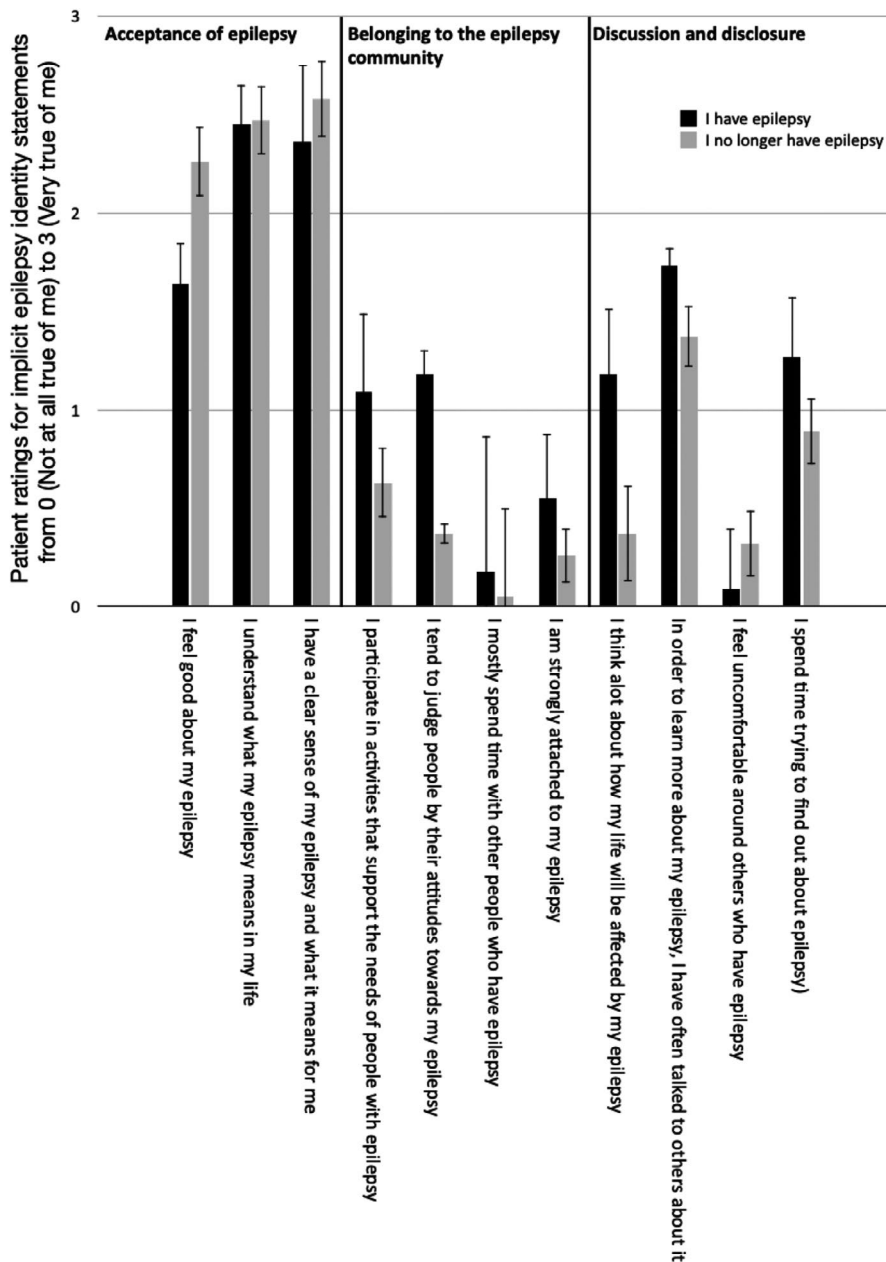


FIGURE 1 Patient responses to statements examining implicit epilepsy identity, showing differences according to explicit epilepsy identity (black vs gray bars)

In terms of implicit SEI, a greater acceptance of epilepsy was significantly associated with reduced anxiety, whereas discussing and disclosing epilepsy was significantly positively correlated with anxiety and negatively correlated with the total QOLIE-31 scores, social functioning, and concern about the effects of medication (Table 3). No aspect of implicit SEI was associated with patient perceived improvements in psychosocial functioning.

3.7 | Explicit SEI mediates the impact of seizure outcome on HRQoL

Given the established relationship between post-surgical seizure outcome and HRQoL^{13,41,42} and the associations found here between seizure outcome and explicit SEI,

and between explicit SEI and HRQoL, a post hoc analysis was run to test if explicit SEI mediates the relationship between seizure outcome and HRQoL. Hierarchical regression analysis was chosen given that the outcome variable (HRQoL) was continuous in a model with both continuous and ordinal data. Regression revealed a significant association between seizure outcome and the QOLIE-31 subscales of seizure worry ($b = -0.39$, $t(29) = 18.1$, $p = .029$), concern about the effects of medication ($b = -0.41$, $t(29) = 7.45$, $p = .019$), and social functioning ($b = -0.39$, $t(29) = 10.0$, $p = .027$). Explicit SEI was added to each regression in a stepwise fashion and was found to mediate the relationship between seizure outcome and seizure worry and concern about the effects of medication, but not mediate the relationship between seizure outcome and social functioning (Figure 2).

TABLE 3 Correlation analyses of explicit and implicit aspects of social epilepsy identity (SEI)

Explicit SEI	Implicit SEI			
	Sense of cure	Acceptance of epilepsy	Belonging to epilepsy community	Discussion and disclosure
Sense of cure	1	.187	.030	−.063
Acceptance of epilepsy		1	.000	.000
Belonging to epilepsy community			1	.000
Discussion and disclosure				1
Quality of life				
Total QOLIE-31	.381*	.211	−.113	−.392*
QOLIE-31 Energy	.295	.178	.103	−.264
QOLIE-31 Quality of life	.493**	.184	.098	−.342
QOLIE-31 Social functioning	.408*	.188	−.096	−.407*
QOLIE-31 Emotional well-being	.351	.355	−.082	−.141
QOLIE-31 Cognitive functioning	.094	.068	−.250	−.321
QOLIE-31 Seizure worry	.592**	.240	.132	−.157
QOLIE-31 Medication effects	.565**	.275	−.002	−.399*
QOLIE-31 Physical health	.216	.147	.194	−.141
Mood				
NDDI-E	−.246	−.331	.148	.205
PHQ-GAD-7	−.117	−.389*	.201	.362*
Patient-perceived psychosocial improvements				
General health	.267	.041	.090	−.200
Seizure control	.579**	.220	.036	.151
Ability to reduce medication	.685**	.222	−.080	.022
Memory/thinking	.050	−.160	−.265	−.129
Social life	.067	−.025	−.020	−.322
Job options	.314	.138	.064	−.116
Standard of living	.241	.001	.085	−.103
Ability to drive	.516**	.113	.108	−.080
Independence	.363*	.077	.182	−.142
Personality	.126	.133	−.066	−.349
Self-confidence	.206	.003	.162	−.110
Romantic relationships	.038	.107	−.096	.030
Family life	.055	−.100	−.021	−.154
Ability to have children	−.011	.132	−.160	−.162

The significant ($p > .05$) values are indicated in bold.

Abbreviations: NDDI-E, Neurological Disorders Depression Inventory-Epilepsy; PHQ-GAD-7, Patient Health Questionnaire for Generalised Anxiety Disorder-7-Item; QOLIE-31, Quality of Life in Epilepsy Inventory-31-item.

* $p < .05$; ** $p < .01$.

4 | DISCUSSION

This was the first study to examine social epilepsy identity (SEI) 15–20 years following epilepsy surgery. In a nuanced exploration of SEI, we examined both “explicit”

identification as someone with epilepsy as well as “implicit” aspects of identity such as patients’ acceptance of epilepsy, sense of belonging to the epilepsy community, and concern about discussing and disclosing epilepsy. At long-term follow-up, 25% of our patients had been free

of disabling seizures since their operation; yet 65% felt that they no longer had epilepsy. Identifying as someone without epilepsy was associated with a higher HRQoL at long-term follow-up, over and above the impact of seizure outcome. Irrespective of SEI, none of our patients regretted the decision to undergo surgery and more than 90% were satisfied with their lives after the operation. This is consistent with previous findings that a sub-optimal outcome does not preclude an individual from reporting satisfaction with surgery.^{8–10,19,43}

Contrary to expectations, we did not find a strong association between explicit and implicit aspects of SEI. Although this may seem counterintuitive, the multidimensional nature of social identity means that explicit and implicit aspects of identity can diverge, often in the face of changes in psychosocial or sociocultural contexts. For example, ethnic identity researchers have found that

some individuals may choose to no longer explicitly identify with their nationality of origin following migration due to experiences of stigma and discrimination, but will continue to actively participate in their ethnic community and/or cultural traditions.^{4,5} Similarly, our patients may no longer explicitly identify as someone with epilepsy (explicit SEI), particularly if they are not experiencing seizures, as this “label” may have been associated with experiences of stigma and/or discrimination. However, they can continue to be interested in research about epilepsy, donate to or volunteer with community epilepsy organizations, or some may still hesitate to discuss their previous diagnosis with new employers or acquaintances (implicit SEI).

Although the social identity literature has also shown that one's biology (eg, race or sex at birth) does not always align with one's social identity (eg, ethnic or gender identity),^{4,23} we found a strong association between clinical epilepsy-related factors and SEI here. Patients who achieved a better seizure outcome, had a longer period of seizure freedom prior to taking part in the study, and were taking fewer ASMs were more likely to show explicit and implicit features of identifying as someone without epilepsy.

Patient-perceived ability to reduce medication post-surgery had the strongest association with the ability to discard an explicit SEI. Findings from the mediation analysis showed that discarding an explicit SEI, associated with a sense of being “cured” following surgery, could reduce the salience of AED use and side effects on patient HRQoL. Reductions in ASMs and their associated side effects following surgery have consistently been related to improved HRQoL, with previous research suggesting that ASMs can serve as an ongoing “reminder” of epilepsy, even for those patients who have attained a good level of seizure control.^{41,44} Our findings would align with this. Taken together, this highlights the importance of understanding and carefully managing patients' expectations to reduce or cease ASMs in pre-surgical counseling.⁴⁵

Being able to explicitly identify as someone without epilepsy post-surgery promoted greater HRQoL and an increased sense of independence at long-term follow-up. Explicitly discarding the SEI (or the sense of being “cured”) was found to mediate the relationship between seizure outcome and aspects of HRQoL. This highlights the importance not only of seizure outcome itself, but of how patients view and interpret this outcome. In seeking to explain this finding we looked to the broader epilepsy literature. Previous studies have highlighted the uncertainty and fear of seizures as a particularly disabling aspect of the condition.^{46–48} One strategy adopted by patients for regaining control following a diagnosis

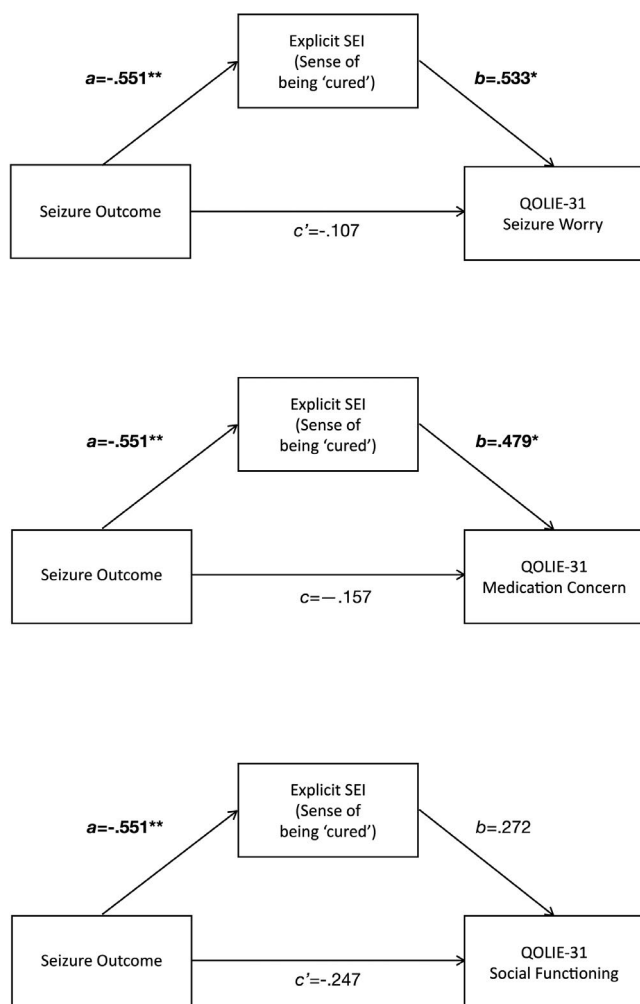


FIGURE 2 Results of the mediation analysis, showing the relationship between seizure outcome, explicit SEI (reflecting a sense of cure following surgery), and QOLIE-31 scores. *Note.* QOLIE-31 = Quality of Life in Epilepsy Inventory – 31-Item. * $p < .05$; ** $p < .0$

of epilepsy is to identify a cause or explanation for why their seizures occurred. These self-generated control perceptions are considered adaptive responses to stress, and often the medical plausibility of these explanations is less important than the psychological sense of control that comes from identifying a cause.^{49–51} In this way, viewing surgery as a curative procedure may foster a greater sense of personal control, thus promoting greater wellbeing. In the current study, 11 patients who experienced rare post-operative seizures (58% of this group) reported that they did not have epilepsy at long-term follow-up. Moving forward, it would be valuable to explore how this group make sense of and explain the experience of rare post-surgical seizures as part of the process of no longer identifying as someone with epilepsy.

With regard to implicit SEI, we found an association between acceptance of epilepsy, increased length of time since the last seizure, and reduced anxiety. One explanation of these findings is that positive reflection on one's epilepsy is boosted by “rosy retrospection,” given the last seizure was a more distant memory. A tendency for patients to reflect positively on the role that epilepsy has played in their life aligns with previous findings from our group demonstrating a complex process of meaning making and psychological reframing following surgery.²² In contrast, attitudes toward discussing and disclosing epilepsy were significantly associated with higher anxiety and poorer HRQoL at long-term follow-up, likely reflecting ongoing difficulties with stigma for those who felt they needed to disclose that they have (or had) epilepsy. These findings align with previous research discussing both personal and social identity in epilepsy in terms of the impact of stigma,^{1,27,52} and add to a wealth of literature emphasizing the impact of broader psychosocial factors, including important social roles, on postoperative HRQoL.^{1,14,25,27,46,47} Our findings also point to the potential for surgery to alleviate some of the felt stigma associated with epilepsy for those able to “shed” their SEI.

4.1 | Strengths and limitations

It should be noted that the final sample, those who were able to complete the online survey, were younger and better educated than the overall cohort recruited. Caution should therefore be taken before generalizing the findings, as our final sample was relatively small for quantitative analysis. However, given the theoretical coherence of our findings, we do not believe that this is a critical flaw, rather a consideration for future research extending this approach.

Our study also highlighted the benefits of the *Living with Epilepsy* program for future research. Researchers are

often faced with increasing rates of attrition, particularly at longer-term follow-up, even when participants have been followed up semi-regularly.^{10,28} Use of an online survey increases ease-of-access for patients who have relocated or who cannot easily attend the hospital or research institute, as may be common for patients with epilepsy who are unable to drive. Furthermore, with the increased use of technology in research and daily life, difficulties accessing online surveys will prove less of a barrier over time.

4.2 | Considerations for future research

A key finding from the current study was that the occurrence of rare post-surgical seizures did not preclude an individual from feeling as though they no longer have epilepsy. Further investigation could focus on understanding how some patients are able to reframe the occurrence of post-surgical seizures, allowing them to mitigate the impact of seizures on identity and well-being. Within the broader illness identity literature it has been shown that seeking explanations for ambiguous outcomes serves to reduce distress, and the medical soundness of explanations is often less important than the ability to identify a specific explanation.^{48,53} Recruitment of a control group of patients who achieve good seizure control on medication (ie, a “mixed outcome” on medication group) would also help to delineate the specific impact of surgery on patient identity.

Social identity is developed through engagement in social roles and relationships. Family support and relationship dynamics pre- to post-surgery has emerged time and again as important factors for patient well-being, as well as playing a key role in post-surgical psychosocial adjustment.^{16,17,54} Navigating the complex process of identity reconceptualization affects the broader family dynamic and family members themselves, including spouses, parents, siblings, and children.⁵⁴ Further exploration of the perspectives of spouses and/or family members and examination of a possible shared process of adjustment would be a valuable addition to the literature.

5 | CONCLUSION

The current findings are a valuable contribution to the epilepsy surgery literature, improving our understanding of the impact of epilepsy surgery on patient identity over the longer-term. Findings emphasize the importance of understanding the psychological complexities associated with living with, and treating, chronic illness and the

importance of understanding patient perspectives of their outcomes for promoting greater well-being. Our findings may also open avenues for clinical intervention through active work with patients exploring their identity and social roles post-surgery.

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CONFLICTS OF INTEREST

None to report.

ORCID

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

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

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

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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