

# Identifying the trajectory of social milestones 15-20 years after epilepsy surgery: Realistic timelines for postsurgical expectations

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## Abstract

**Objective:** Patients often undertake epilepsy surgery with the expectation that it will lead to improvements in their social situation. Short- to medium-term research consistently points toward improvements in social outcomes; however, no study has mapped out postsurgical social timelines, particularly for longer-term (>15 years) outcomes.

**Methods:** We recruited 39 patients who had undergone anterior temporal lobectomy (ATL) for drug-resistant temporal lobe epilepsy (TLE) between 1994 and 2002. The cohort (24 females) had a median age of 49 years (range 38-67), age of habitual seizure onset was 9.5 years (range 0.5-29 years), and age at surgery was 31 years (range 20-53). Patients were followed up for a median of 18.4 years postsurgery (IQR = 4.4). Using data obtained from semistructured interviews, we conducted a comprehensive qualitative analysis of patients' self-reported postsurgical social trajectories. Self-report questionnaires were used to assess mood and health-related quality of life (HRQOL) at the time of interview.

**Results:** There was a common sequence of social milestone achievement, spanning 20 years postsurgery. Typically, patients first (re)gained their license, then attempted educational and vocational gains, followed by establishing long-term relationships and finally a family unit. Rare, intermittent seizures postsurgery did not appear to have detrimental effects on social trajectories. Those who experienced a reduction in seizures showed increased likelihood of attaining social milestones compared to those with ongoing seizures.

**Significance:** Achieving social milestones after epilepsy surgery may take considerably longer than patients are expecting prior to surgery. The pattern of social milestone outcome resembled a process of psychosocial development. These findings have important implications for presurgical counseling and postsurgical rehabilitation.

## KEYWORDS

epilepsy surgery, social outcomes, long-term follow-up, qualitative, patient perspective

## 1 | INTRODUCTION

Surgery is currently the recommended treatment for eligible patients with drug-resistant epilepsy.<sup>1</sup> While the primary objective is to reduce seizures, surgery can also significantly impact psychosocial functioning.<sup>2-4</sup> Research has identified a number of common expectations held by patients regarding their postsurgical outcomes.<sup>5,6</sup> Alongside freedom from seizures and reduced antiepileptic drugs (AEDs), patients commonly expect improvements in their social functioning in the form of increased opportunities for driving, employment, interpersonal relationships, and social activities.<sup>7-9</sup> Such expectations often reflect important social milestones that individuals may have felt impeded in attaining as a result of their epilepsy. Indeed, a study of adolescents and young adults with temporal lobe epilepsy (TLE) found reduced achievement of key social milestones compared to age-expected levels.<sup>10</sup>

Following successful surgery, achievement of these milestones can provide a benchmark by which patients measure the success of the operation.<sup>11</sup> Furthermore, many patients express a desire to “catch up” on important social milestones and may, as a result, take on too much, too quickly, during the recovery period.<sup>2</sup> Overall, research shows improvements in driving, employment and rates of marriage following epilepsy surgery,<sup>12,13</sup> which are associated with improved health-related quality of life (HRQOL), particularly for patients who achieve seizure freedom.<sup>14</sup> The majority of studies to date, however, have focused on psychosocial outcomes two to five years postsurgery, with fewer investigating long-term outcomes, particularly over a 20-year period.<sup>3,5</sup> This presents a drawback, as this time frame is unlikely to be sufficient for patients to accomplish more complex social milestones, such as upskilling for alternative employment opportunities, or the formation of intimate relationships and a family unit. For example, a study by Sperling and colleagues found that patients may take up to six years to gain employment postsurgery.<sup>15</sup>

There has also been relatively less exploration of long-term family and interpersonal outcomes<sup>3</sup> and a lack of in-depth qualitative exploration. Combined, this has precluded the careful mapping of comprehensive long-term postsurgical social trajectories, including the order and time frame of achieving social milestones. This information is vital for patient counseling. We therefore sought to better understand the long-term (15-20 years) social outcomes of epilepsy surgery, by systematically mapping the pattern of achievement of postsurgical social milestones. It was hypothesized that there would be identifiable patterns in achievement of social milestones across long-term postsurgical follow-up, as well as commonalities in patient descriptions of these trajectories. We also hypothesized that these patterns would be impacted by seizure outcome in systematic ways.

### Key Points

- A common sequence was observed in long-term postsurgical social trajectories of ATL patients
- The trajectory of social milestones spanned 15-20 years postsurgery
- This trajectory resembled a process of psychosocial development
- Patients with sporadic, breakthrough seizures described a similar pattern to seizure-free patients
- Patients with ongoing seizures had impoverished social outcomes

## 2 | METHODS

### 2.1 | Follow-up procedure and recruitment

Epilepsy diagnosis is confirmed at the time of initial enrollment to the Austin Health Comprehensive Epilepsy Program (CEP) according to established methods,<sup>16</sup> including clinical, EEG, neuroimaging, and neuropsychological investigation. Postsurgery, patients undergo routine medical, neurological, neuropsychological, psychiatric, and psychosocial follow-up.<sup>2,17</sup> The long-term follow-up process for patients who have undergone anterior temporal lobectomy (ATL) through Austin Health has been described previously.<sup>18,19</sup> Briefly, patients enrolled in the CEP undergo routine psychosocial follow-up for 24-months postsurgery. Some patients receive clinical follow-up for longer, with 32% of those in the current study consistently followed up between 2 and 7 years. After the initial 24-month period, all patients are contacted biannually by telephone if they have not been in contact with Austin Health in the interim period, to obtain information on their general outcomes and the possible occurrence of postoperative seizures.

This study was approved by the Human Research Ethics Committees of Austin Health and The University of Melbourne, Australia. Inclusion criteria were as follows: (a) a single documented ATL for drug-resistant TLE, (b) age  $\geq 18$  years at the time of surgery, (c) a functional level of English, and (d) absence of a documented intellectual disability (ID). These criteria reflected the ethical approvals of the study and requirement of participants to engage in lengthy interview that included long-term recall of past events, as well as the possible altered social trajectories of individuals with ID, which may be independent of epilepsy.<sup>20</sup>

Recruitment occurred between 2014 and 2016, starting with review of patient records and ending when qualitative theme saturation was met. One hundred and fourteen patients were identified as having undergone a single ATL between 1994 and 2004 (to ensure a follow-up of  $\geq 15$  years). Of these,

one had died, four were lost to hospital contact, and 27 did not meet other inclusion criteria. Seventy eligible patients were contacted via post in a consecutive manner, beginning with those who underwent surgery in 1994 (Figure S1). Forty-five (60%) agreed to participate. The remaining patients could not be contacted ( $n = 18$ ), declined due to perceived time commitment ( $n = 6$ ), or reported a negative experience of surgery ( $n = 1$ ).

## 2.2 | Participants

Following recruitment, one patient did not return the consent form, three withdrew due to time constraints, and one patient was unable to be scheduled for interview. For the current study, one further patient was excluded post-interview as a significant outlier on all quantitative measures. This resulted in a final sample of 39 ATL patients (23 females; 25 left-sided), with a median follow-up of 18.4 years (IQR = 4.4), representing a large cohort for qualitative analysis.<sup>21,22</sup> All patients gave informed consent in accordance with the Declaration of Helsinki.

## 2.3 | Seizure outcome

It has been suggested that use of stricter definitions of seizure freedom may result in the reporting of greater improvements in vocational outcomes.<sup>15</sup> We therefore chose a less stringent approach, similar to that of Sperling et al. Based on patients' long-term follow-up records, seizure outcomes were classified as: (a) seizure free (SF)  $\pm$  auras, (b) mixed outcome (MO); one or more extended periods of seizure freedom  $\geq 5$  years, and (c) ongoing seizures (OS); no period of seizure freedom  $\geq 5$  years.

Comparison of those who were excluded ( $n = 27$ ) or did not participate in the current study ( $n = 31$ ) versus those who did ( $n = 39$ ) revealed a significant difference in seizure outcome ( $X^2(4) = 10.64, P = 0.03$ ). Those who participated were more likely to have a MO (SF: 26%, MO: 59%, OS: 15%) compared to those who did not participate (SF: 39%, MO: 26%, OS: 35%) and were more likely to have a better seizure outcome than those who were excluded (SF: 15%, MO: 52%, OS: 33%).

## 2.4 | Measures

Postsurgical psychosocial functioning was assessed using a modified version of the Austin CEP Interview, a well-validated, qualitative interview for epilepsy surgery patients.<sup>11,17,23,24</sup> For the current study, minor adjustments were made to assess outcomes over a longer follow-up period. The use of open-ended questions allows for spontaneous accounts of social outcomes rather than a specific focus predetermined by the researchers. Follow-up prompts

allowed for exploration of core issues documented in the epilepsy surgery literature, if not already raised by the patient, including (a) educational and vocational activities, (b) relationships and family dynamics, and (c) social activities. Interviews were conducted by the same researcher (HC), either face to face ( $n = 7$ ) or via telephone ( $n = 33$ ), and took approximately 90 minutes each (SD = 30). Interviews were supplemented by questionnaires assessing current symptoms of depression, anxiety, and HRQOL.<sup>25–27</sup> Details of these measures can be found in Table S1.

## 2.5 | Data analysis

Patient interviews were transcribed and entered into Nvivo 11 (QSR International Pty Ltd). A *data set* was extracted from the overall *corpus* (all data collected using the Austin CEP interview), representing all instances of patients discussing social milestones.<sup>28</sup> These milestones (Table 1) were identified from a careful review of the literature examining chronic illness and psychosocial functioning.<sup>10,29,30</sup> Due to time constraints, assessment of vocational outcomes focused predominantly on the job the patient held at the time of interview.

### 2.5.1 | Achievement of social milestones

Information extracted from patient interviews was corroborated against medical records where possible, and social milestones were mapped according to years postsurgery.

### 2.5.2 | Qualitative analysis of patient experiences

A thematic content analysis was used to gain a richer understanding of patient perspectives of achieving postsurgical social milestones. We took an explicit thematic approach, which aims to classify data into meaningful and relevant categories for participants. This approach is well suited to the analysis of semistructured interviews.<sup>28,31</sup>

Data were first coded inductively, line by line, and common themes were sought within and between codes.<sup>28</sup> A thematic content analysis can also involve quantifying themes and subthemes, as a method of highlighting the primary issues. Thematic saturation occurred when the examination of new interviews did not reveal any further themes.

### 2.5.3 | Secondary quantitative analysis of seizure outcome

Quantitative analyses were conducted using IBM SPSS Statistics (Version 24). All tests were two-tailed with a 5% significance level. Due to the uneven distribution and relatively small numbers across seizure outcome groups, assumptions of parametric tests were not upheld and more conservative

Domain	Specific milestones	Description
Social	Driving	Receiving medical clearance to drive or obtain a learner's permit
	Drugs and alcohol	Use of alcohol and/or recreational drugs
	Friendships/social activities	Establishing and maintaining friendships and hobbies
	Travel	Interstate or overseas travel
Educational	Furthered education	Pursuing secondary or tertiary education or a trades certificate
Vocational	New job/promotion	Commencement of the job the patient was in at the time of study interview
	Stopped working	Stopped work due to redundancy, retirement, or commencing disability support
Family	Relationship conflict	Disruption of relationship dynamics following surgery
	Separation/divorce	Separation or divorce from long-term partner/spouse
	New relationships	Establishment of the relationship/marriage the patient was in at the time of study interview
	First children	Birth of first child postsurgery for those married (m) and single (s) at the time of surgery

**TABLE 1** Social milestones assessed following surgery

nonparametric alternatives were employed.<sup>32</sup> Kruskal-Wallis tests were used to assess group differences in mood, anxiety, and HRQOL, with post hoc Mann-Whitney *U* tests used to identify the direction of between-group differences.

### 3 | RESULTS

#### 3.1 | Pattern of postsurgical social milestone trajectories

Driving, education, employment, and family milestones were easily time-tagged events and could be plotted across the long-term follow-up period (Figure 1; see Figure S2 for individual milestones). Milestones relating to alcohol and/or recreational drug use, social activities or hobbies, and travel were not plotted due to difficulty identifying specific dates. These outcomes were, however, still included in the thematic analysis.

A particular pattern, or sequence, of social milestone achievement was identified (Figure 1). Patients focused early on driving, before moving on to educational and vocational milestones, followed by family milestones. This pattern spanned the length of the follow-up period.

##### 3.1.1 | Driving

Twenty-nine patients (74%) had obtained a license prior to surgery. For two (5%), a seizure-related car accident triggered initial investigation of surgery. Following surgery, 28 (72%) regained their license or obtained a

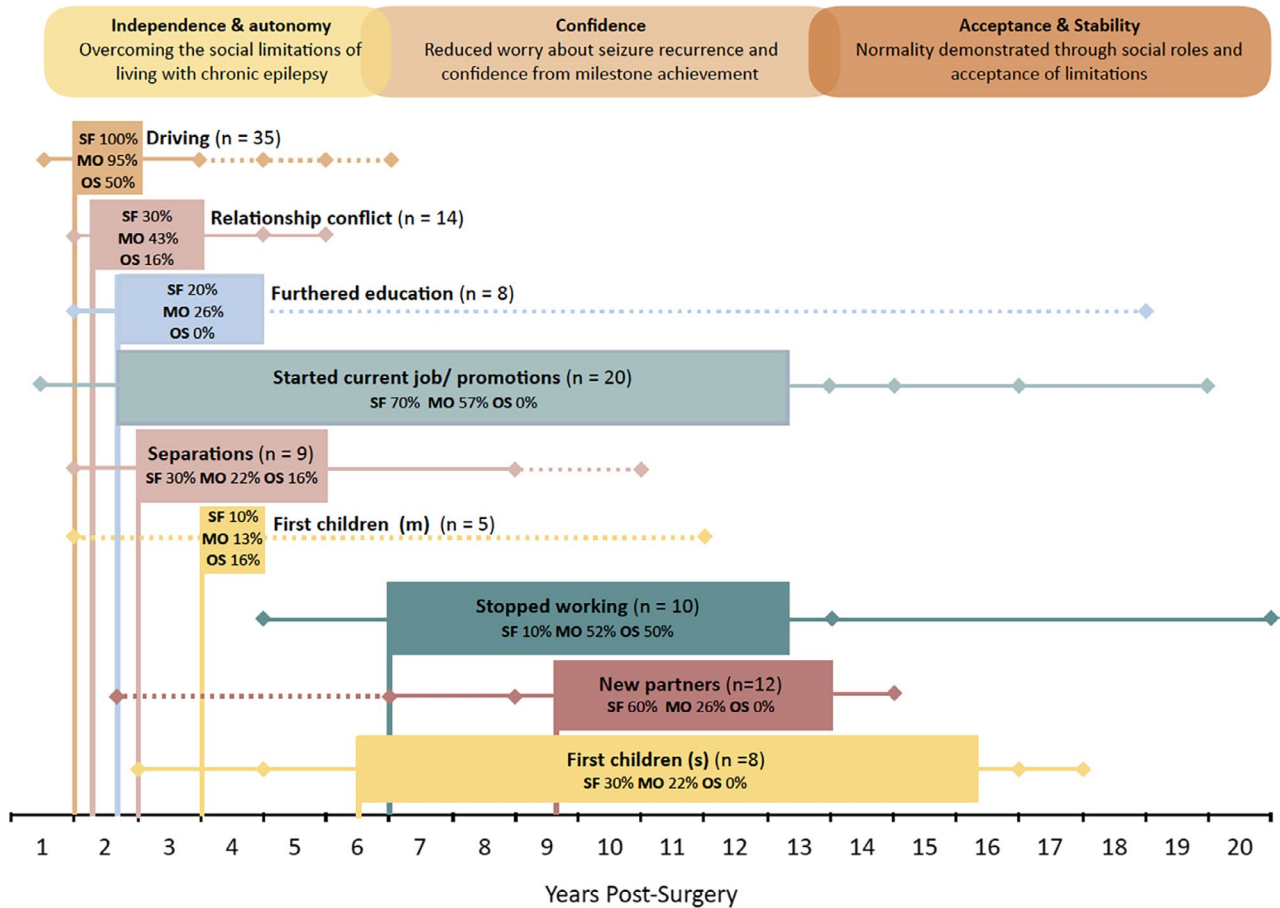
learner's permit within 24 months. Seven (18%) obtained their license between 2 and 6 years postsurgery, while four (10%) were not driving at the time of interview due to seizures or, in the case of one MO patient, out of choice. Three (50%) of the OS group were able to regain their license due to a shift to nocturnal seizures ( $n = 1$ ) and periods of seizure freedom  $\leq 5$  years ( $n = 2$ ). However, they were not able to hold their license over the entire follow-up period.

##### 3.1.2 | Relationship conflict and separations

Half of the patients in a relationship at the time of surgery (14/26; 54%) reported altered relationship dynamics, which included relationship conflict due to the postsurgical adjustment process. For five patients (20%), this led to separation, typically occurring within five years of surgery. A further four patients (16%) separated from partners within 10 years of surgery but did not link this to postsurgical adjustment. The majority of those who separated subsequently established new long-term relationships (55%), and one MO patient reconciled with her partner following a year of separation.

##### 3.1.3 | Furthered education

Patients embarked on achieving educational milestones typically within four years of undergoing surgery. Eight (21%) reported furthering their education in the form of



**FIGURE 1** Post-surgical social milestones mapped according to the years they were accomplished. Outliers represented by individual diamonds; SF, seizure free; MO, mixed outcome; OS, ongoing seizures; (m), married; (s), single. Percentages represent the proportion of patients within each group who achieved each milestone.

completing high school certificates (n = 1, MO), trade certificates (n = 5), undergraduate (n = 1, SF), or postgraduate (n = 1, MO) University degrees. Three patients (8%) were considering pursuing further education at the time of interview to enhance their vocational prospects.

### 3.1.4 | Work and promotions

Medical records indicated at least 23 (59%) patients underwent a graded return to work within 24 months of surgery; however, at the time of interview only 11 (28%) specifically mentioned this process. Patients commenced the job they were in at the time of interview between 2 and 12 years postsurgery, with median time since commencing their current job at 10 years (SD = 5.4). Of those unemployed at interview (n = 16), three (19%) were unemployed prior to surgery and did not gain ongoing employment postsurgery. Those who stopped working after surgery did so between 6 and 12 years—one became a primary carer (MO), three (19%) retired, and nine (56%) went onto a disability support pension.

### 3.1.5 | New partners

Approximately a third of patients (n = 13) were single at surgery. Establishment of long-term romantic relationships, both for those who were single (9/13; 69%) and for those who found new relationships following early separations (5/9; 55%), typically occurred nine or more years postsurgery. Only one patient (SF) established a new relationship within 2 years postsurgery that was ongoing at interview.

### 3.1.6 | First children

Approximately half of those in a relationship at the time of surgery had children (14/26; 54%), while five (19%) had their first child postsurgery, typically within 3-4 years. Of those who were single at surgery (n = 13), three (23%) had children within six years, and five (38%) had children 15 or more years postsurgery. Three patients (23%) became stepparents, 10-14 years postsurgery. Ten patients (27%) did not have children, 50% of whom had OS.

### 3.2 | Impact of seizure outcome on social outcomes

Clinical and social outcomes are outlined in Tables 2 and 3, respectively. Unsurprisingly, there was a significant difference between seizure groups in AED use, with SF patients more likely to have discontinued AEDs and OS patients more likely to be on polytherapy. OS patients also had significantly less time elapsed since their last seizure.

Seizure free and MO groups demonstrated good social milestone achievement across the follow-up period. A higher proportion of SF patients established new relationships, while more MO patients stopped working postsurgery. However, a higher proportion of MO patients were slightly older and already married at surgery. In contrast, the OS group described relatively impoverished social trajectories and showed significantly reduced social milestone achievement at interview (Table 3).

### 3.3 | Patient perceptions of their social trajectories

Patient experiences of achieving social milestones were grouped under four broad themes: early independence, growing confidence, acceptance and stability, and an underlying sense of caution (Table 4).

#### 3.3.1 | Early independence

Early social milestones, particularly driving, were associated with an increased sense of independence and autonomy.

Themes of exploring this autonomy were raised by 80% of SF and 83% of MO patients, compared to 33% of the OS group. Driving in particular was remembered as the first major achievement and a tangible sign of independence. Patients also recalled catching up on missed opportunities and/or exploring opportunities not previously available, including the ability to travel, which was often described as a highlight.

A downside to this newfound independence and autonomy was its potential to result in relationship conflict in the early years postsurgery. Partners were sometimes (15%) described as “carers” presurgery and subsequently struggled to accept patients' increased independence and associated changes in behavior. At the time of interview, five patients (13%) also described fractured dynamics in their family of origin. These difficulties were present for two families prior to surgery; however for the others, families could also have difficulty accepting changes in the patient's attitudes or behaviors following surgery, and they could view the patient's changes in relationships as out of character, resulting in strained family dynamics. Evidence of fractured dynamics up to 20 years postsurgery points to lasting changes in patient support networks as a result of the postsurgical adjustment process.

The sense of increased independence was not absolute. For example, two MO patients (9%) reported the need to consider the risk of seizures when on holidays (eg, not being allowed to snorkel). OS patients particularly experienced more limitations around driving, including driving restricted to the daytime (16%) or experiencing periods of being unable to drive postsurgery due to seizures (33%). Three OS patients (50%) were unable to regain a driver's license, which significantly impeded their ability to establish

	Seizure free (n = 10)	Mixed outcome (n = 23)	Ongoing seizures (n = 6)
Gender (female)	7 (70%)	14 (61%)	2 (33%)
Laterality (left)	8 (80%)	14 (61%)	3 (50%)
Presurgery GTCS	3 (30%)	7 (30%)	4 (67%)
Medication regime <sup>a</sup>			
No AEDs	4 (40%)	4 (17%)	0
Monotherapy	6 (60%)	15 (65%)	1 (17%)
Polytherapy	0	4 (17%)	5 (83%)
Mean current age (SD)	48.4 (4.5)	51.3 (8.6)	54.9 (7.2)
Mean age at surgery (SD)	29.2 (4.6)	33.6 (9.8)	37.2 (7.1)
Mean age at onset (SD)	10.4 (5.7)	11.8 (8.7)	19.7 (15.9)
Mean duration of preoperative epilepsy (SD)	18.9 (7.1)	22.2 (10.8)	17.5 (13.2)
Mean length of follow-up (SD)	19.1 (1.3)	17.3 (2.8)	17.5 (2.1)
Mean time since last seizure (SD) <sup>a</sup>	19.2 (1.5)	10.9 (6.9)	1.5 (3.1)

**TABLE 2** Clinical and seizure characteristics of participants according to seizure outcome for the final sample (n = 39)

Abbreviations: AEDs, antiepileptic drugs; GTCS, generalized tonic-clonic seizures; SD, standard deviation.

<sup>a</sup>*P* < 0.005.

**TABLE 3** Social demographics based on seizure outcome for the final sample (n = 39)

	Seizure free (n = 10)	Mixed outcome (n = 23)	Ongoing seizures (n = 6)
Marital status at surgery			
Single	4 (40%)	5 (22%)	4 (67%)
Partner	2 (20%)	4 (17%)	2 (33%)
Married	4 (40%)	14 (61%)	0
Current marital status <sup>b</sup>			
Single	0	0	5 (83%)
Partner	2 (20%)	4 (17%)	0
Married	7 (70%)	17 (74%)	0
Divorced	1 (10%)	1 (4%)	1 (17%)
Widowed	0	1 (4%)	0
Have children/stepchildren	8 (80%)	20 (87%)	1 (16%)
Living arrangements <sup>b</sup>			
Partner and/or children	8 (80%)	22 (96%)	0
Parents	0	0	2 (33%)
Alone	2 (20%)	1 (4%)	4 (67%)
Currently Driving <sup>b</sup>	9 (90%)	22 (96%)	3 (50%)
Highest level of education			
Primary school	1 (10%)	1 (4%)	0
Secondary school	5 (50%)	11 (49%)	3 (50%)
TAFE	3 (30%)	3 (13%)	1 (17%)
University	1 (10%)	8 (34%)	2 (33%)
Current occupation <sup>b</sup>			
Employed FT	6 (60%)	13 (57%)	0
Employed PT	3 (30%)	1 (4%)	0
Unemployed	1 (10%)	6 (26%)	6 (100%)
Retired	0	3 (13%)	0
Median NDDI-E (IQR)	10.0 (4.0)	11.0 (6.0)	10.5 (8.0)
Median PHQ-GAD-7 (IQR)	2.0 (4.0)	2.5 (8.0)	0 (11.0)
Median Total QOLIE-31 (IQR)	79.6 (12.4)	81.6 (17.4)	67.9 (24.1)
Median QOLIE-31 social functioning (IQR) <sup>a</sup>	95.0 (15.0)	98.0 (15.0)	68.5 (63.8)
Median QOLIE-31 seizure worry (IQR)	100.0 (8.9)	100.0 (10.8)	83.0 (18.4)
Median QOLIE-31 medication concern (IQR) <sup>a</sup>	100.0 (2.8)	80.6 (47.9)	63.9 (52.1)

Abbreviations: FT, full time; NDDI-E, Neurological Disorders Depression Inventory for Epilepsy; PHQ-GAD-7, Patient Health Questionnaire for Generalized Anxiety Disorder—7-item; PT, part-time; SD, standard deviation; QOLIE-31, Quality of Life in Epilepsy Inventory—31-item; TAFE, Technical and Further Education.

\* $P < 0.05$ .

\*\* $P < 0.005$ .

independence as they continued to rely on the assistance of family and/or friends.

### 3.3.2 | Growing confidence

As assurance in newfound independence and autonomy grew, so did patients' confidence in their ability to manage new social roles. Confidence was strengthened twofold, through reduced fear of seizure recurrence and through important social achievements, such as furthering education,

successful return to work, promotions, or new social hobbies. These achievements were sources of pride and stood out as important accomplishments, or specific new adventures that were not possible prior to surgery (15%). Themes relating to increasing confidence were raised primarily by SF (80%) and MO (78%) patients. Only one OS patient (16%) specifically described building confidence through social roles.

Surgery also had a noticeable impact on being a parent. Four patients (31%; all female) felt epilepsy had impacted their ability to parent, which negatively impacted their

**TABLE 4** Commonly reported themes when discussing social milestones (n = 39)

Theme	n (%)	Subtheme	Examples
Early independence & Autonomy	Own independence 29 (77%)	Driving the first major milestone	S034 (SF): That was the biggest, first thing to come out of the whole thing was clearance there [to drive].
		Driving increases social and vocational opportunities	S022 (SF): Like when I first got my license I think I just called in on so many people to see if they were home, [...] whereas before [...] I'd even have to get a cab to basketball to play and a cab home.
		Catching up	S011 (MO): I was on fast-forward; I was sort of catching up everything that I'd missed. Relationships and all that. And socialising.
	Impact on others 13 (36%)	Friends adjusting to changes in patient	S007 (MO): Took a lot of people time to adjust to me being quote, unquote normal again.
Family adjusting to changes in patient creates conflict		S014 (SF): Especially my husband, it affected him a lot because he was so used to coping and having to do things and we went through stages there where you just sort of argue about everything because he was so used to just being able to do it [...] whereas you know, you're trying to be more independent.	
Growing confidence	Confidence 25 (64%)	Long-term social restrictions	S050 (OS): Because I don't have a license [...] If you don't have a license, you lose your independence and you gotta rely on people, basically.
		Through successes in new social roles	S018 (MO): I'm more confident in what I do, where I go. Like, I remember I was working and [...] my cousin [...] loaned me a car and I drove to [town], stayed overnight [...] I would never have done that if I still had epilepsy.
	Hurdles 19 (49%)	Through reduced worry about seizures	S056 (MO): Like you can get on with life and not have to stop to think, "Oh I might have a seizure."
		Due to age and maturity	S059 (MO): Just with being older and, and yeah, more in control I suppose.
Acceptance and stability	Current normality 35 (90%)	Ongoing epilepsy-related challenges in social roles	S022 (SF): I haven't really got any social friends down there. And you know, I don't know whether that extends back from, you know, your confidence with having epilepsy and all the rest, you know, that it's harder, you know.
		Financial difficulties	S066 (MO): Oh, I wish I didn't have to [work]. Wish I didn't have to earn money but you know, I was off a long time when I had seizures, so it's my turn to pay a little bit back, I feel.
	Reframing 19 (49%)	Disclosure or discrimination in the workplace	S035 (MO): I didn't know whether to be 100% truthful or not, you know, because I've been seizure free for so long I didn't know if it was necessary to bring that up [for a job application].
		Work and family life illustrate normality	S037 (MO): Yeah, yeah, working full-time and yeah, and that, general house and kids and family stuff, so yeah.
Acceptance and stability	Reframing 19 (49%)	Reframed early relationship conflict	S024 (MO): That's probably the biggest downside to the operation. But the, I'm remarried um, which was inevitable given my scenario. I'm with someone a bit, bit more in tune with me, physically and mentally.
		Overcome delays in achieving family milestones	S006 (SF): But back then [post-op] I was depressed because there wasn't anybody in my life. I'd think I'm getting older and older and I don't want to be alone for the rest of my life. It was more that side of things.
		Social comparisons	S034 (SF): If I was me brother, who's two or three years older than me, he had [a] kid when he was 18 who's like 21, 22 now, so, whereas I'm like 42 and I've got a four-year-old.

(Continues)



TABLE 4 (Continued)

Theme	n (%)	Subtheme	Examples
	Acceptance 27 (69%)	Accepted social limitations	S059 (MO): I'm not terribly sociable [...] I'm not good at making friends and that sort of thing but I work with another four ladies my age and we all seem to get on.
Ongoing caution	For self 29 (74%)	Alcohol and drugs linked to seizure risk	S046 (MO): 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.
		Important to maintain license	S056 (MO): I'd rather take a tablet and not have a seizure then find out and have a seizure. I can lose my license.
	For others 3 (8%)	Risk of passing epilepsy on to children	S049 (OS): Well I've also vowed never to have any children. Cause I don't want to pass any epilepsy on to somebody else.

self-esteem. Postsurgery, reduced worry about seizures gave parents the confidence to take on more responsibility at home. For those without children at surgery ( $n = 26$ ), nine (35%) reported that a good seizure outcome gave them confidence to start a family with less concern about the added burden on their partner.

Despite this growing confidence, social achievements were not without challenge. Nine patients (23%) reported that epilepsy had impeded their education before surgery and eight (20%) reported they could subsequently not “be bothered” furthering education postsurgery, as it represented too great a challenge. Postoperative cognitive difficulties interfered with the pursuit of further education for two patients (5%), and one MO patient reported having to change jobs as a result of postsurgical memory issues. Memory difficulties were particularly evident at work (46%); however, these difficulties were primarily attributed to aging, tiredness, or the side effects of medication, rather than to surgery.

Disclosure and/or discrimination in the workplace remained an issue—four patients (10%) cited perceived discrimination or occupational health and safety issues due to their epilepsy as the reason they stopped work postsurgery. Patients also faced the new challenge of deciding whether to disclose that they *have* or *had* epilepsy to new employers. Financial issues were also raised by 22 patients (56%) and were cited as a reason for working long hours or delaying retirement, potentially reflecting levels of underemployment.

### 3.3.3 | Acceptance and stability

Themes of acceptance and establishing stability were raised by SF (100%), MO (96%), and OS (50%) patients. Social roles, particularly relating to family and work, were key to stability, often illustrating life as “normal.” Comparison to friends and family helped patients situate themselves within a broader social network (better than some, worse than others), but highlighted perceived delays in social milestone achievement. Patients commented on the experiences of living at home for longer than their siblings, and feeling

relatively inexperienced and delayed when exploring romantic relationships and starting their own family. For those who experienced significant changes in their family dynamics, reframing also fostered acceptance. Patients reframed postsurgical difficulties as an “inevitable” part of the adjustment process, for the better. “For the better” could include either a reestablished, more equal partnership dynamic, dissolution of the relationship and finding a new, more compatible partner, or enjoying being single.

Presurgery, 13 patients (33%) specifically reported the desire to expand their social horizons. At the time of long-term interview, however, many patients (44%) described limited social circles outside of the family because they were “introverted” or “shy.” Difficulties included not knowing how to meet new people and make small talk, as well as experiencing poor memory for names, which could result in social embarrassment. Only three patients (8%) felt they should be socializing more, and overall, there was no evidence of a need to “catch up” on social activities at the time of interview.

### 3.3.4 | Ongoing caution

A sense of caution continued across the follow-up period, including concern that stress from social roles could trigger seizures, as well as fear that a seizure would result in social restrictions. These themes were raised by 60% of SF patients, 74% of MO patients, and 100% of OS patients.

Despite early expanding social horizons, only three patients (8%) reported “catching up” on partying or excessive alcohol use. Seven (18%) reported abstinence from alcohol and 17 (44%) had never tried recreational drugs, primarily due to the perceived increased risk of seizures, a feeling of already taking “enough drugs,” and/or general lack of interest. Those who experimented with recreational drugs ( $n = 5$ ; 13%) reported cannabis use only.

Risk of seizure recurrence remained at the “back of the mind” for patients, even after long periods of seizure freedom, with seven (18%) reporting an ongoing fear of losing their driver's license. Strategies to manage this concern

included not wishing to change AED regimes, not drinking and driving, and maintaining general health. Three patients (8%) also reported concern about the possible heritability of their epilepsy, which was a reason not to have children for one OS patient.

### 3.4 | Mood, anxiety, and HRQOL

Given the potential impact of current psychiatric symptoms on cognitive function and day-to-day activities, we investigated group differences in mood, anxiety, and HRQOL (Table 3). A significant difference was only found for the QOLIE-31 subscales of social functioning ( $H(2) = 6.63$ ,  $P = 0.036$ ) and concern about the effects of medication ( $H(2) = 8.36$ ,  $P = 0.015$ ). Post hoc Mann-Whitney  $U$  tests revealed less concern regarding medication for the SF group compared to MO ( $U = 61.5$ ,  $P = 0.022$ ,  $r = -0.40$ ) and OS patients ( $U = 6.0$ ,  $P = -.004$ ,  $r = -0.53$ ). The OS group showed significantly lower scores on social functioning compared to both SF ( $U = 9.0$ ,  $P = 0.02$ ,  $r = -0.43$ ) and MO patients ( $U = 26.5$ ,  $P = 0.017$ ,  $r = -0.44$ ).

## 4 | DISCUSSION

We examined patient experiences of their postsurgical trajectory of social milestone achievement over a 15-20 year follow-up period. Driving was described as the first major milestone postsurgery. Patients then addressed educational, vocational, and family goals. The timing of a return to driving is in part dictated by local medicolegal regulations; however, few patients delayed regaining their driver's license beyond 24 months. This supports the importance of pursuing this milestone early and its role as a major accomplishment for patients and an important stepping-stone to other social achievements.<sup>33</sup> Pleasingly, the number of patients who had achieved driving (87%) and new employment outcomes (51%) exceeded estimates of patients who expected these outcomes in a previously published TLE cohort from Austin Health (45% and 35%, respectively).<sup>8</sup> This cohort also commonly expressed a desire to develop new activities (38%)<sup>8</sup>; however, only 15% of our patients specifically raised the topic of starting new hobbies postsurgery, while 44% reported accepting limited social circles.

It has been suggested that there is stability in patient-perceived benefits, satisfaction, and HRQOL across short- and longer-term postsurgical follow-up due to a reprioritization effect.<sup>34</sup> In other words, a stable sense of HRQOL may be fostered by the mutual adjustment of expectations and perceptions of postsurgical experiences, such as the acceptance of social limitations described above.<sup>35</sup> In our study, patients reframed early difficulties or delays in milestone achievement

as an inevitable part of their journey toward better outcomes, or adjusted expectations retrospectively to accept ongoing seizures and associated restrictions. A recent qualitative study of the long-term outcomes of epilepsy surgery identified a similar process to that described by our cohort,<sup>9</sup> supporting an active reframing and reprioritization of ongoing progress postsurgery, in order to maintain psychosocial “equilibrium” as patients work toward achieving their social goals.

To date, studies of patient expectations have largely focused on the number of patients reporting specific goals, rather than exploring the time frame within which patients believe they will achieve these goals. Expecting changes to occur within a short time frame may heighten patient disappointment and frustration following surgery. Indeed, patients who emphasize family and social expectations presurgery are less likely to consider their operation a success at six-month follow-up.<sup>11</sup> The postsurgical social trajectory identified here spanned the 20-year follow-up period, which has important implications for patient counseling. Patients who view surgery as a final resort and delay undergoing the operation may be at particular risk of perceiving heightened delays after surgery when comparing their achievements to those of friends and family.

The pattern of social outcomes identified here strongly resembles a process of psychosocial development, in which individuals move through sequential stages, each involving a particular task, or role, to master.<sup>36</sup> Of relevance to our patients, individuals can be prompted to revisit particular stages following major life events, such as epilepsy surgery, and seek to readdress the task or remaster the role.<sup>36</sup> Following surgery, aspects of the early process of adjustment, known as the burden of normality,<sup>2,23,37</sup> resemble the psychosocial stage of identity formation, in which individuals explore new social roles and form a “well” identity.<sup>38</sup> This was evident in patient recall of early experiences of questioning their sense of self without epilepsy, increased self-expectations, a need to make up for lost time, excessive activity, and the restructuring of family dynamics, all core features of the burden of normality.<sup>2</sup> After this stage of identity formation, individuals typically address the challenge of learning to commit to others in partnership.<sup>36</sup> Interestingly, for those patients who were in a relationship at the time of surgery, conflict and separations occurred predominantly *within* 5-10 years of surgery and for those who were single at surgery, new relationships were predominantly established 10 years *after* surgery. It may be that establishing a new relationship is more easily achieved after an individual has been able to explore and establish his or her own identity, strengthening the idea of a stage-based, or stepwise psychosocial process. At the time of long-term interview, established families, as well as work roles, were commonly used to illustrate a sense of stability, or normality in current life. This broadly aligns with the appropriate

stage of middle adulthood, in which the focus is on contributing to society and the next generation.<sup>36</sup> Conceptualizing the long-term postsurgical adjustment process within a psychosocial framework provides clinicians with a broad structure from which to explore patient postsurgical goals and outcomes.

Of note, sporadic breakthrough seizures did not appear to significantly impact the social outcome trajectory, providing support for the idea that complete seizure freedom is not a necessary condition for social benefits following surgery.<sup>3,13,39</sup> The recurrence of regular ongoing postoperative seizures, however, did present barriers to milestone achievement. Within the OS group, establishing stability or normality appeared primarily driven by a process of “getting on with it” and accepting seizure recurrence, as described by Shirbin et al.<sup>40</sup>

#### 4.1 | Strengths and limitations

Qualitative studies provide a rich, in-depth perspective of the lived experiences of a specific population, in this case those who have undergone epilepsy surgery. In such research, a specific “control” group, healthy or medical, is typically not relevant.<sup>31,40–48</sup> Moreover, while the social milestones examined here, including divorce and fractured family dynamics, are common across any population, what we have described are changes in social trajectories that patients attribute to the process of undergoing surgery. From these lived experiences, the lifespan developmental framework of Erikson emerged as relevant, given its broad account of a typical psychosocial trajectory that serves as a useful point of reference, including the tendency of individuals to revisit earlier phases where developmental tasks or milestones have not been realized.<sup>36,49</sup>

It should be noted that those who participated in the final study were less likely to have ongoing seizures compared to those who were excluded. Overall, however, the majority of our patients had a mixed seizure outcome, experiencing some seizure recurrence. In fact, the highest rate of seizure freedom was seen in those who declined to participate, suggesting that our sample is not merely reflective of those with the “best” outcome. In addition, the proportion of patients achieving seizure freedom, as well as specific social milestones across our seizure outcome groups, are largely consistent with previously published ATL cohorts.<sup>4,50,51</sup> Our work extends this literature by focusing on characterizing the pattern and psychological experience of social milestone achievement and the impact of seizure outcome on this pattern. Importantly, these findings may not only be useful for clinicians treating patients with epilepsy. Research into the early postsurgical adjustment process has been found to translate well to other neurological conditions, such as Parkinson's patients undergoing deep brain stimulation, or patients with successfully treated narcolepsy.<sup>52–55</sup>

## 5 | CONCLUSION

This study is one of the longest post-ATL follow-up studies to date. It provides a unique, patient-centered perspective for understanding the pattern of postsurgical social outcomes, including realistic time frames for achieving key social milestones following surgery. These findings may be used to inform clinical practice in terms of improved presurgical counseling of patients and families, as well as postoperative follow-up and rehabilitation.

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### CONFLICTS OF INTEREST

None to report. 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.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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