Examining quality of life in an Australian cohort of people with epilepsy over six years – understanding the role of stigma and mood

Honor Coleman [a,b,c], Chris Peterson [b,d] & Christine Walker [b,e]

[a] School of Psychological Sciences, The University of Melbourne, Parkville, Australia

[b] Epilepsy Foundation, Surrey Hills, Victoria, Australia

hcoleman@epilepsyfoundation.org.au

[c] Department of Neuroscience, Faculty of Medicine, Nursing and Health Sciences, Monash University, Melbourne, Australia

[d] School of Humanities and Social Sciences, La Trobe University, Bundoora, Australia

c.peterson@latrobe.edu.au

[e] Chronic Illness Alliance, Moonee Ponds, Australia

cwalker@chronicillness.org.au

*Corresponding author

Honor Coleman

University of Melbourne

honor.coleman@unimelb.edu.au

Abstract

Aim. Research examining quality of life (QoL) among people living with epilepsy (PWE) consistently highlights the detrimental impact of stigma, anxiety and depression, as well as the dynamic and changing nature of QoL over time. This paper represents the first panel study of the Australian Epilepsy Longitudinal Survey (AELS), examining factors that influence the QoL of PWE over a six-year interval, particularly focusing on experiences of stigma, depression and anxiety.

Methods. Ninety-two adults participated in both Wave 2 (T1; 2010) and Wave 4 (T2; 2016/17) of the AELS. Average age at T2 was 53.4 years [SD=15.3; range 22-82; 55% Female]. Over the study interval, there was a shift towards more younger participants moving out of high school and older participants moving into retirement. We explored the impact of (i) experiences of stigma (ii) mood, and (iii) sociodemographic factors on QoL at both T1 and T2 via the use of correlation analyses. Hierarchical regression was used to determine the strongest predictors of QoL at T2.

Results. Occurrence of recent seizures, stigma, anxiety and depression measured at T1 were all significantly correlated with total QoL at both T1 and T2. Sociodemographic factors including years of education, weekly income before tax, and weekly income before tax were not significantly correlated with QoL at either T1 or T2. QoL and depression at T1 were identified as the strongest predictors of QoL at T2 (six years later).

Discussion. The current study supports previous research highlighting the importance of psychological factors in understating QoL in PWE, particularly stigma, anxiety and depression. In particular, it highlights the impact of depression on QoL over a 6-year interval, providing evident for the long-term nature of this relationship.

Key Words. Quality of life. Stigma. Depression. Longitudinal research.

Introduction

There is a wealth of research focused on identifying factors that may impact quality of life (QoL) in people living with epilepsy (PWE), including factors related to seizures and seizure treatment, factors associated with the comorbidities of epilepsy such as cognitive difficulties, depression, anxiety, and sleep difficulties, as well as broader psychosocial factors such as self-efficacy and financial vulnerability have also been investigated (1–6). This research is valuable for guiding quality improvement in the treatment and support options available to PWE.

In a comprehensive analysis of QoL trajectories among PWE, Jacoby and Baker (2008) highlighted the dynamic and changing nature of QoL in response to changes in seizure frequency, for example following a first seizure versus after treatment with surgery for those living with chronic treatment-resistant epilepsy (7). As the authors note, however, this work represents a synthesis of the findings of cross-sectional studies. Prospective data is critical to furthering our understanding of factors that impact QoL over time (7). More recently, Puka et al. (2020) published a comprehensive study examining QoL trajectories of children living with epilepsy over a ten-year period following diagnosis (8). Factors that were associated with poorer QoL trajectories included presence of cognitive and psychiatric comorbidities and poorer satisfaction with family dynamics, including increased depressive symptoms for parents (8). To date, however, there is very little prospective long-term research examining QoL in adults and exploring factors that may influence QoL over time.

The Australian Epilepsy Longitudinal Survey (AELS) was set up to better understand the perspectives and experiences of a community sample of PWE. An important part of this has been the prospective collection of longitudinal data on psychosocial factors that may play an important role influencing the well-being and QoL of PWE. The current study therefore set out to examine QoL over time, particularly focusing on the role of stigma and mood on QoL over a six-year interval. It was predicted that both experiences of stigma and increased depression would be the strongest predictor of QoL at the time of measurement (T1) and would also significantly predict QoL six years later (T2).

Methods

Study Design

The Australian Epilepsy Research Register (AERR) is an Australian-wide research register run by the Epilepsy Foundation, which is open to people living with epilepsy as well as family/ carers/ friends of people living with epilepsy. For those PWE who have volunteered to be on the AERR, basic demographic information and contact details are kept on the register in order to contact them regarding opportunities to participate in research. In particular, participants on the AERR are invited to participate in the Australian Epilepsy Longitudinal Study (AELS). The AELS is an observational longitudinal study that involves a series of survey 'Waves'. That is, a set of survey questionnaires collecting sociodemographic and psychosocial data are sent out every three years. The AELS does not involve routine access to participant medical records or clinical information, the surveys are self-report only. The first survey "Wave" (or set of questionnaires) was sent out in 2010. Participation in these Waves is voluntary. Ethics approval was gained from Deakin University Human Ethics for both Wave 2 (HREC No: 2009-213) and Wave 4 (HREC No:2013-011), and all participants give informed consent.

This study presents an analysis of a sub-set of AELS participants who were identified as having provided answers across both Wave 2 (2010) and Wave 4 (2016/17). The relevant waves have been designated as T1 (Wave 2, 2010) and T2 (Wave 4, 2016/17). This is the first Panel design study to be published on longitudinal data arising from the AELS. In order to examine changes in QoL over time, particularly focusing on the impact of stigma on QoL, we compared the experience of stigma at T1 to QoL at both T1 and T2. Data from Wave 3 (2013) was not included in the current study because it did not include a measure of QoL. Further details of the surveys sent out at T1 and T2 can be found in Table 1.

Of the total 736 participants who responded to Wave 2 and/or Wave 4, 92 were included in the current study. Participants were included if (i) they completed both survey waves (n=101) and (ii) if they were ≥16 years due to the need to complete a self-report measure of QoL.

[Table 1 here]

Participants

Information on the participants who completed both Wave 2 and Wave 4 can be seen in Table 2. The sample had an average age of 46.1 years [SD=15.5; range 16-75] at T1 and 53.4 years [SD=15.3; range 22-82] at T2..A slight shift can also be seen towards more of the younger participants moving out of high school and more of the older participants moving into retirement over the study interval.

[Table 2 here]

Measures

Questionnaires were distributed to participants of the AERR, either via mail or online (Survey Monkey) in 2010 (T1) and 2016/17 (T2) canvassing the areas outlined in Table 1. Of particular relevance to the current study, stigma was measured in Wave 2 via a self-report scale of stigma experiences, mood was measured via the Hospital Anxiety and Depression Scale (HADS), and QoL measured in both waves using the Quality of Life in Epilepsy Inventory-31 items (QOLIE-31).

Self-report Stigma Scale

The measure of stigma was adapted from Austin et al. (2004), who developed a scale for measuring stigma in children with epilepsy and their parents. This was chosen due to the lack of brief, targeted measures of stigma in the adult epilepsy population at the time of the survey (2009/2010). Austin et al.'s (2004) scale was developed in a cohort of children with new-onset seizures (n=224) and their parents (n=173) and further tested in a chronic sample (9). Using a 5-point Likert scale, this scale measures both feelings and associated behaviours in relation to stigma. Higher scores reflect greater perception of stigma. The original scale has been found to have good content and construct validity and internal consistent reliability (9). The wording of items from this scale were adapted for an adult cohort, as has

been reported in previous publications from the AELS (10) and Cronbach's alpha was calculated to examine the internal consistency of the scales identified in the current study (see Results).

The Hospital Anxiety and Depression Scale (HADS)

The HADS is a self-assessment scale that was developed to detect heightened symptoms of anxiety or depression in the setting of an hospital medical outpatient clinic. This survey allows us to present comparisons of those with no anxiety to those with mild to greater anxiety using a cut-off point of 8 or higher (range: 0–21) and, similarly, comparing levels of depression also with a cut-off point of 8 or higher (range: 0–21). The cut-off point of 8 for the Anxiety and Depression subscales was chosen as this has been shown to be a more optimal balance of sensitivity and specificity (11). The scale has demonstrated good reliability and validity, and has been used extensively in the chronic illness literature (10,12,13).

In the 2010 Wave 2 Survey, there was a minor variation in the presentation of the HADS, as reported in previous publications from the AELS (10,14). Specifically, participants were asked to reflect on their *current* mood rather than being directed to answer how they have been feeling in the past week and due to the layout of the survey, a number of respondents missed item 6 (see Supplementary Information for further information). Missing data relevant to the current analyses is reported in the relevant tables.

The Quality of Life in Epilepsy-31 Item (QOLIE-31)

The QOLIE-31 has been used extensively in the epilepsy literature to investigate the impact of a range of factors on QoL, including affective symptoms (15,16). The overall QOLIE-31 and sub-scales have been found to demonstrate good internal consistency and test-retest reliability.

For the current study, the total QOLIE-31 score was used at T1 and T2 were used. As noted in Table 1, there were some slight anomalies in the wording of the QOLIE-31 distributed at T1, for example changes in the labels given to Likert scale numbers ("Always" instead of "All of the time"). These differences are detailed further in Supplementary Information and were accounted for in calculating the total score.

Data Analysis

Quantitative analyses were undertaken with the statistical package SPSS Version 24 (IBM Corp. 2016, NY). All tests were two-tailed, and a 5% significance level was used throughout.

In order to examine patient responses regarding their experiences of stigma, a principal component analysis was run on all nine statements using varimax rotation. Principal Components Analysis (PCA) is a dimension-reduction technique used to simplify the internal structure of the data by identifying underlying factors that account for the variance seen across participant responses to individual questions. Kaiser-Meyer Olkin measure was 0.865, indicating good sampling adequacy, and Bartlett's test of sphericity was significant $p>.000$, supporting use of a PCA.

Frequencies and bivariate correlations were then used to examine the relationship between the resulting principal components and measures of mood and QoL. A hierarchical regression analysis aimed to determine key predictors of QoL, specifically examining the impact of stigma, anxiety and depression at T1 with QoL at T1 and T2.

Results

Delineating experiences of stigma at T1

Examination of responses regarding experiences of stigma revealed a two-factor solution, based on Kaiser's criteria of eigenvalues over 1 and supported by examination of the scree plot. This explained 77.6% of the variation in the data. Items in each factor can be seen in Table 3. The first component included six items reflecting concern about how other people perceive their epilepsy and about potential discrimination as a result. This was therefore labelled "Perceived Stigma." The second component included three statements reflecting the individual's level of embarrassment about their epilepsy and associated concealment behaviours. This was therefore labelled "Internalised Stigma." Examination of Cronbach's alpha revealed good internal consistency of both scales, sitting at .93 for Perceived, and .91 for Internalised Stigma. These factors were saved as variables to further examine the relationship between perceived and internalised stigma at T1 and QoL at T1 and T2.

[Table 3 here]

Exploring changes in QoL over time

Mean total QOLIE-31 score increased from T1 (M=58.42, SD=16.94, n=93) to T2 (M=63.86, SD=15.71, n=92). A paired-sample t-test revealed that this was a significant difference ($t(91)=-3.64$, $p=.000$), and bivariate correlations revealed a significant positive correlation between QoL at T1 and QoL at T2 ($r=.620$, $p=.000$, $n=98$).

Number of seizures in the previous 12 months, stigma, anxiety and depression as measures at T1 were all significantly correlated with total QoL at both T1 and T2 (Table 4). However, the strength of all associations appeared to lessen at T2. Of note, number of seizures in the previous 12 months was only measured at T1 (i.e., across 2009) but still had a significant effect on QoL six years later. As such, it may be assumed that these PWE experience poorer control over their seizures generally.

The following factors were not correlated with QoL at either T1 or T2; years of education (T1), weekly income before tax (T1), duration of epilepsy (T1), or weekly income before tax (T2).

[Table 4 here]

All of the significant factors associated with QoL (outlined in Table 4) were then entered into a hierarchical regression with stepwise entry to determine the most significant predictors of QoL at both T1 and T2.

Model for QoL at T1

The final model for predicting QoL at T1 revealed a four-factor solution ($F(4,79)=26.25$, $p=.000$, $R^2=.58$, $R^2_{\text{Adjusted}}=.56$). Factors that emerged as the strongest predictors of QoL at T1 were symptoms of depression (ß=.-.40, $t(79)=-4.24$, $p=.000$), followed by anxiety (ß=-.29, $t(79)=-2.90$, $p=.005$), how many

seizures they had experienced in the past 12 months (ß=-.20, $t(79)=-2.62$, $p=.011$), and finally perceived stigma (ß=-.18, $t(79)=-2.14$, $p=.036$).

Model for QoL at T2

The final model revealed a three-factor solution ($F(3,78)=25.31$, $p=.000$, $R^2=.50$, R^2 Adjusted=.48). Factors that emerged as the strongest predictors of QoL at T2 were QoL at T1 (ß=.65, $t(x)=6.55$, $p=.000$), followed by age at first seizure (ß=.23, $t(78)=2.99$, $p=.004$), and symptoms of depression at T1 (ß=.90, $t(78)=2.01$, $p=.048$).

Discussion

This is one of the first studies to examine the evolution of QoL over time in an Australian community cohort of PWE, identifying key factors that influence QoL over a six-year interval. In particular, our findings highlighted the stable nature of QoL over time given the strongest predictor QoL at T2 was QoL at T1. While symptoms of depression appeared to have a stable negative influence on QoL over time, the influence of anxiety appeared to lessen over time.

The impact of stigma on QoL

Our findings highlighted the significant impact of the experience of stigma on patient well-being. Not only was both perceived and internalized stigma associated with lower QoL at T1 (2010), it was also significantly correlated with poorer QoL six years later, at T2 (2016/17). The impact did, however, appear to lessen over time, with stigma more strongly correlated with QoL at T1 compared to T2. Stigma is a well-researched construct in the field of epilepsy, given the long and complicated history of misunderstanding and discrimination experienced by this population and the known deleterious effect that it has on an individual's well-being (14,17). The experience of stigma in epilepsy has consistently been linked to clinical factors such as seizure frequency and severity and AED use, as well as psychosocial factors such as lower socioeconomic status, poor access to medical services, as well as depression and anxiety (7,18–20).

A well-known model of stigma in epilepsy is Graham Scambler's "hidden distress model," which differentiated between felt and enacted stigma (21). Enacted stigma refers to actual instances of discrimination against PWE, such as unfair dismissal from work, while felt stigma refers to the perception

of stigma from others and/or fear of encountering possible enacted stigma. Some researchers also describe internalized stigma, whereby an individual absorbs negative attitudes about their condition and therefore his/herself as a result of their experiences (21,22). Among our cohort felt stigma appeared to have a greater impact on QoL than did internalized stigma. In other words, the fear of possible exclusion and/or discrimination from others had a greater negative impact on the wellbeing of our cohort compared to the sense of embarrassment or need to disclose their diagnosis. These findings could be considered consistent with the body of research examining the psychosocial impact of social exclusion and isolation (23–26). This research has been in strong focus in recent months due to the COVID19 pandemic and increasing focus on the effects of loneliness and social isolation.

Protective factors that can mitigate the experience of stigma have been identified in the literature, including social support and family cohesion, as well as knowledge of epilepsy on behalf of the PWE and their family (7,8,20). This research has enabled the development of educational programs, which have been found to reduce the experience of stigma for PWE in developing countries (27).

Stigma has also been shown to be a dynamic process, reactive to changes in the individual's health status and broader social environment. In line with this, some researchers have identified changes in the experience of stigma over time, with one study identifying a decrease in perceived stigma among children with time since diagnosis (28). Interestingly, in our cohort, perceived stigma appeared to affect QoL over a six-year interval, although it was not the strongest predictor based on the hierarchical regression. One explanation for this may be differences between individuals who have experienced their first seizure and those with chronic epilepsy. For example, individuals who have experienced a first seizure often experience a dip in mood and QoL in response to the sudden, and sometimes traumatic, onset of seizures (13,29) but with good seizure control, QoL often returns to normal (7,8). Individuals with chronic epilepsy, who may be considered more likely to engage in ongoing community research with the AERR over many years, often show poorer long-term QoL trajectories. Those PWE living with chronic or more complex epilepsy may therefore also experience more ongoing concern about the potential negative consequences of stigma.

The lasting impact of depression on QoL

The prevalence of depression among PWE is almost twice that of the general population but it often goes underdiagnosed and treated. Both depression and anxiety have consistently been identified as factors that impact on QoL for both adults and children living with epilepsy. Studies have suggested an equal impact of both, while others have identified a greater impact for depression (5,12,30–32). Overall, these findings contribute to a wealth of literature emphasizing the importance of psychological factors, over and above clinical factors such as seizure frequency, for impacting the QoL of PWE. Increased screening for mood difficulties and greater understanding of factors that may contribute to mood difficulties will enable the development of more targeted and effective treatment. For example, Shallcross et al. (2015) found that negative illness perceptions (e.g., perceptions about the cause, chronicity and complexity of one's diagnosis) mediated the impact of depression on QoL. The authors suggested that targeting these perceptions through approaches such as cognitive behavioural therapy will then be beneficial for mood and QoL (33).

Interestingly, socioeconomic factors did not appear significantly associated with QoL in the current study even though factors such as socioeconomic status, social support and the family environment have all been identified previously as factors that can influence QoL (8). One reason for this may be that our cohort report relatively consistent socioeconomic status with not enough variation across the sample to detect an effect. Furthermore, we did not assess broader markers of social support or family environment, such as family dynamics or satisfaction. This is a focus for future survey waves of the AELS to further delineate the relationship with QoL.

Strengths and Limitations

The current study represents a valuable addition to the QoL in epilepsy literature due to the prospective and long-term nature of the data collected. Many studies examining changes in QoL over time tend to focus on changes over a 24-month period, often following diagnosis or treatment interventions such as surgery (7,34). A further strength of the current study relates to the numbers who participated, supporting the robustness of findings.

Some limitations should also be acknowledged for the current study. As noted in the Methods section, minor wording variations occurred across survey Waves 2 and 4. This is an important matter to note, given

the non-standardized administration of standardized measures may result in difficulties generalizing the current findings. We would note that adjustments to existing measures, such as adapting the Austin Child Stigma Scale for an adult population, has been done by other researchers (e.g., 35) It is also felt that minor variations in the wording of the QOLIE-31 would not have altered how participants interpreted the questions. There has also been research to suggest that minor wording changes do not significantly alter a scale's psychometric properties (36). Furthermore, the relationship between depression and QoL has been found to be robust in spite of the tool used to measure QoL (37). It is important, however, to note these very slight variations in wording in order to increase the transparency of the research process, allowing for the findings to be considered in the context of any potential caveats.

Finally, as discussed above, numerous factors have been identified that may impact QoL and it is likely that other factors are influencing QoL over time in our sample, including presence of comorbidities, family satisfaction and broader social support. It is impossible to examine every factor that may influence QoL, however, and the current study focused particularly on two factors that have been strongly identified in the literature, namely stigma and depression.

Conclusion

The current study is a valuable addition to the QoL literature, highlighting important factors that can influence the QoL for PWE over time. It demonstrates the persisting effects of stigma, and particularly perceived stigma, on the lives of PWE. Further the impact of anxiety especially points to the need for support for PWE affected to reduce harmful effects on QoL over time and training for health professionals working with PWE to understand the unique ways in which epilepsy may impact anxiety (38). More longitudinal research is needed into supports for psychosocial and stigma effects to delineate the relationships between these factors and other clinical and sociodemographic factors such as the type and frequency of seizures.

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Ethical publication statement

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

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could appear to influence the work reported in this paper.

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Tables

Table 1. An outline of the topics covered in the survey Waves of the Australian Epilepsy Longitudinal Study in 2010 (T1) and 2016/17 (T2)

Time 1: Wave 2 (2010)	**Time 2: Wave 4 (2016/17)**
Sociodemographics	Sociodemographics
Epilepsy-related variables	Epilepsy-related variables
Driving and epilepsy	-
Access to treatment and medical care	Access to treatment and medical care
General health and physical illness	-
QOLIE-31	QOLIE-31
HADS	Single question on depression and anxiety
Attitudes and reactions to epilepsy • Have you been unfairly treated due to your epilepsy? ǂ • Have you been unfairly disadvantaged due to your epilepsy? ǂ • Describe what STIGMA means	Equipment and service needs • Have you experienced a recent hospitalisation • What aids and equipment are useful for the management of your epilepsy?

Note. A survey 'Wave' refers to the periodic mail out of a set of demographic and psychosocial questions to a community sample of PWE.

ǂ Qualitative data from these questions has been published previously in Bellon et al. (2013).

Table 2. Demographics (n=93) for adult (≥16 years) PWE who participated at both T1 (2010) and T2 (2016/17) of the AELS.

	T1 (2010) M(SD)/ n(%)	**T2 (2016/17) M(SD)/ n(%)**
Mean age (SD)	46.1 years (15.5)	53.4 years (15.3)
Gender (female)	51 (55%)	50 (54%) [a]
Location (urban)	49 (53%) [b]	60 (65%) [d]
Marital status		
Single	39 (42%)	-
Married	33 (36%)	-
De facto	9 (10%)	-
Separated/ Divorced	11 (12%)	-
Widowed	1 (1%)	-
Living situation		
Own home/ mortgage	57 (62%) [c]	68 (73%)
Renting	18 (19%)	18 (19%)
Other	7 (8%)	
Highest level of education [a]		
<Year 12	47	36
TAFE	10	13
Trade	6	8
Higher Education	29	20
Employed [a]	*46*	*39*
FT	25	17
PT	10	10
Casual	11	12
Unemployed (total)	*46*	*54*
Retired	14	23
Studying	7	0
Home maker	10	9
Receiving benefits (Yes) [a]	45 (48%)	47 (51%)
Absent from work due to seizures in past 12 months (Yes) [c]	18 (19%)	-

Note. FT = Full-time; PT = Part-time; SD = standard deviation; TAFE = Technical and Further Education.

[a] *n*=1 missing

[b] n=19 missing

[c] n=11 missing

[d] n=4 missing

Table 3. The rotated component matrix showing a two-factor solution (factors >.3) reflecting perceived and internalised stigma

	Perceived stigma	**Internalised stigma**
Item		
I feel different from others who do not have epilepsy	**.588**	.401
People will not like me if they know I have epilepsy	**.792**	.396
Other people without epilepsy are uncomfortable with me because of my epilepsy	**.830**	
People will not want to be my friend if they know I have epilepsy	**.868**	.313
People will not want to go out with me if they know I have epilepsy	**.823**	.307
People will not want to invite me to parties if they know I have epilepsy	**.810**	.362
I feel embarrassed about having epilepsy	.459	**.758**
I keep my epilepsy a secret from others		**.906**
I try to avoid talking to other people about my epilepsy		**.921**

Note. The labels 'Perceived' and 'Internalised' stigma were chosen here to align with the broader theoretical framework of Scambler & Hopkins (1986). These factors were also identified by Peterson, Walker & Shears (2014) in a study on Wave 4 data (n=343) and were labelled 'social' and 'personal' stigma.

Table 4. Correlation matrix showing the relationship between perceived and internalised stigma at T1 (2010) and total QoL as measured by the QOLIE-31 at both T1 and T2 (2016/17)

	QoL (T1)	**QoL (T2)**
Age at first seizure (T1)	.190	**.267***
Number of seizures in past 12mo (T1)	**-.264***	**-.295****
QoL (T1)	**-**	**.651****
HADS Anxiety (T1)	**-.621****	**-.370***
HADS Depression (T1)	**.640****	**-.312****
Perceived stigma (T1)	**-.455****	**-.364****
Internalised Stigma (T1)	-.121	-.076

Note. *p<.05, **p<.01