



A longitudinal study over 9 years of the role of social support for people with epilepsy

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Abstract

Aim: In people with epilepsy (PWE), relationships and support are critical. From receiving affection to getting help with household and medical activities, support can increase Quality of Life (QoL) and resilience. This article aims to identify how key sources of support are affected by epilepsy over a 9-year period.

Methods: This longitudinal study is based on a panel of 51 of the same people measured at three points spread over 9 years—Waves 2, 4, and 5 (2010, 2016/7, and 2019/20). The article reports on supportive relationships affected by epilepsy and four different types of support. It investigates the nature and extent of the effects of epilepsy on support for PWE and how these changed over 9 years. The study uses mixed methods.

Results: Measured at Wave 5, affectionate support was the most common, while positive social interaction (PSI) was the least. The study showed that over time, epilepsy was having differential effects on supportive relationships (partnerships and with family and friends). Quantitative results suggest that PWE were coping better over time with the effects of epilepsy on family and friendships. The qualitative analysis showed that in Wave 2 where PWE reported on stigma experienced, it was mainly emotional/informational support, together with some PSI that was evident. In Waves 4 and 5, support including from clinicians and epilepsy associations was presented. Some PWE reported that they wanted emotional/informational support from psychologists/counsellors.

Conclusions: Support from partners changed little due to epilepsy over the 9 years, while the effect of epilepsy on support from family and friends diminished over that time. In order to more fully understand the support needs of PWE, a good grasp of the sources of social support, whether from health professionals, partners, wider family, or friends is required.

Keywords

Mixed methods, social support, stigma



Introduction

Epilepsy is not just a single condition but a group of many different diseases with various underlying mechanisms with associated seizures [1]. A particular problem for people with epilepsy (PWE) is poor social support which can exacerbate problems caused by epilepsy and can lead to diminishing Quality of Life (QoL). An important goal in responding to the condition is enhancing support from partners, other family and friends. The stigma associated with epilepsy may create discrimination in employment and impact social relationships and activities.

This study is an Australian longitudinal panel study over 9 years. Upton and others [2–7] have argued the importance of social support for health, QoL, reduced mortality, and better seizure control [8–12].

Berkman et al. [13] argued the role played by the larger social structure needs to be included as it influences the roles of social support or social networks' impact on health. "By embedding social networks in this larger chain of causation, we can integrate 'upstream' macro-social forces related to the political economy with social networks as mediating structures between the largest and smallest scale social forms" [13]. Berkman et al. and others also pointed out that not all support was positive and that social networks could also be destructive [13–15].

Lahey [16] described social support as three distinct types of support: perceived, enacted or received support, and then social integration. Jacobson [17] pointed out that while researchers counted numbers of supports persons received or wanted, they assumed that all individuals experience support the same way. The stressfulness of an event reflects an individual's appraisal of it, rather than its objective attributes [17].

In this article, we take the insights from these authors to explore the role of supports for PWE, beyond enumerating them. We argue that the need for the type of support may change over time. Using data collected from Wave 2 (2010), Wave 4 (2016/7), and Wave 5 (2019/20) of the Australian Epilepsy Longitudinal Study (AELS), provides the opportunity to explore this. In the three Waves of the AELS there is data on education, employment, family relationships, support, self-efficacy, stress, stigma and the broader socio-political structure, self-reported health, and self-reported support experiences. This longitudinal data allows us to construct a dynamic model of the role of supports in the lives of PWE within the complex and changing social structural environment of Australia.

What has been found in this study that sets it apart is a greater understanding of the long-term effects of epilepsy on personal relationships and how this changes, over time (nine years). The qualitative component also drew on stigma, an experience requiring support, and on later use of professional help services to identify modes of support needed or utilised over time.

This study hypothesises the negative effects of epilepsy on relationships (partner, family, and friends) will diminish over time, while the need for support remains (Waves 2–5). We cite Manacheril et al. [18] who posit that a longer lead time in coping with negative social experiences affects QoL.

Materials and methods

The AELS is a survey conducted every three years employing repeated measures to understand the impact of epilepsy on individuals. These repeated surveys are known as Waves. This is a panel study consisting of the same people from Waves 2 (2010), 4 (2016/7) and 5 (2019/20). Participants are recruited from the Australian Epilepsy Research Register (AERR) which commenced in 2006. Informed consent was gained from participants and ethics clearance was gained by Deakin University Australia (HREC 2013-011). There were no concerns about confidentiality. There are 51 of the same participants, all included in Waves 2, 4, and 5. The Waves 1 and 3 were not included as the sample size of the panel would be reduced to 15–20, precluding most forms of analysis. Also, these Waves did not contain all the support variables that the included Waves did. A flow chart (Figure 1) is included to show the years of data collection in this longitudinal study.

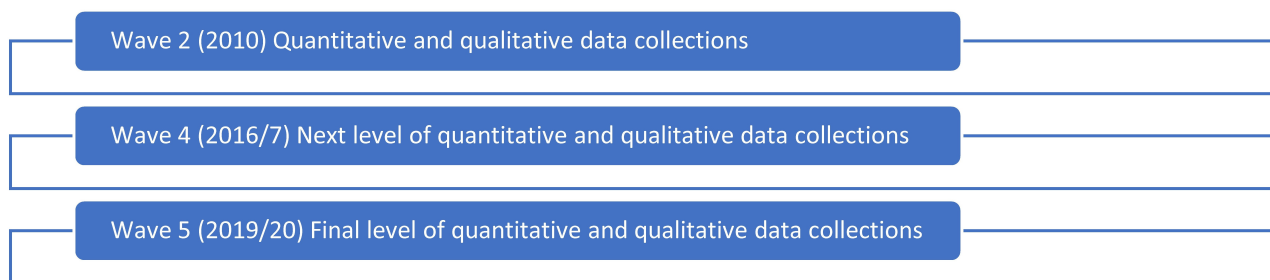


Figure 1. Flow chart of data collections

In Wave 5 of the AELS, the Medical Outcomes Study Social Support Survey (MOS-SSS) was used to measure the following social support dimensions: affectionate support; tangible support; emotional and informational support; and finally positive social interaction (PSI); to have fun with others/another. The scale showed internal consistency. That is reliability (Cronbach’s alpha) of the scales ranges from 0.91 and higher and inter correlations are 0.72–0.90 [19]. One item from the RAND Social Support Scale (MOS) is missing in our study due to a technical problem: item no. 7 in the Emotional/Informational Support Scale—‘Someone to turn to for suggestions about how to deal with a personal problem’.

Waves 2, 4, and 5 have variables consisting of supportive relationships with partners, family, and friends. For the analysis of the effects of epilepsy through support, scales were created for these three variables for Waves 2, 4, and 5. Wave 2 scale of supportive relationships had a relatively strong Cronbach’s alpha (where the same result would be expected with multiple samples) of 0.85, Wave 4 was 0.85, and Wave 5 was 0.87.

All three Waves contain qualitative responses indicating how people feel about living with epilepsy and where they seek support. These were analysed using grounded theory techniques [20, 21] by CW and CLP independently and then categorised according to the MOS-SSS social support dimensions. To build a dynamic model of support, both qualitative and quantitative data are situated in an analysis of the broader structure of QoL, education, and employment, and finally the overarching social structure and the changes impinging on responses from 2010 and 2019/20.

There are frequency analyses together with measures of percentage change in supportive relationships and other aspects of life affected by epilepsy between Wave 2 and Wave 4, as well as Wave 2 and Wave 5. These relate to measuring changes in the effects of epilepsy and support. Quantitative data analysis was undertaken using SPSS Version 27.0 (2020 Armonk. NY: IBM Corp).

Results

The age range in Wave 2 is 20–75 years (see Table 1). These are the same people in all three Waves. The highest level of education, employment, and current non-employed status (such as retired) are all reported.

Table 1. Waves 2, 4, and 5 socio-demographics

Demographic	Wave 2 (2010)	Wave 4 (2016/7)	Wave5 (2019/20)
Age [Mean Median (SD) Range]	46.39 [51.0 (15.56) 20–75]		
<i>n</i>	51		
Gender			
Female	26 (51.0%)		
Male	25 (49.0%)		
Highest level of education			
Year 12 or lower	27 (52.9%)	21 (41.2%)	21 (41.2%)
TAFE/Trade	6 (11.8%)	11 (21.5%)	8 (15.6%)
Tertiary	17 (33.3%)	18 (35.3%)	20 (39.2%)
Missing	1 (2.0%)	1 (2.0%)	2 (4.0%)

Table 1. Waves 2, 4, and 5 socio-demographics (*continued*)

Demographic	Wave 2 (2010)	Wave 4 (2016/7)	Wave5 (2019/20)
Employment			
Paid employment	27 (52.9%)	21 (41.2%)	21 (41.2%)
Full-time employed	16 (59.3%)	11 (52.4%)	12 (57.2%)
Part-time employed	6 (22.2%)	5 (23.8%)	5 (23.8%)
Casually employed	5 (18.5%)	5 (23.8%)	4 (19.0%)
Others			
^a Retired	10 (19.6%)	11 (21.6%)	9 (17.6%)
Unable to work due to epilepsy	7 (13.7%)	6 (11.8%)	6 (11.8%)
Not working due to a disability	4 (7.8%)	5 (9.8%)	5 (9.8%)
Seeking paid employment	0	0	2 (3.9%)
Homemaker	3 (5.9%)	3 (5.9%)	6 (11.8%)
Missing	0	5 (9.8%)	2 (4.0%)

^a Outside of work columns (e.g., retired, unable to work due to epilepsy, etc.) percentages do not add up to 100% but individually they are portions of the total sample; SD: standard deviation

Analysis commenced with quantitative data. Overall, types of support, reported in Wave 5 (2019/20) were used as an analytic tool, mainly in the qualitative analysis.

Support

Table 2 shows that PWE had the highest amount of affectionate support (74.84) (where a score of 0 indicated no support and 100 a lot of support). The least amount of support PWE received was for PSI. The highest scoring emotional/informational item was ‘Someone you can count on to listen to you when you need to talk’, ‘Someone to take you to the doctor if you needed it’ was the highest item of tangible support. ‘Someone to love and make you feel wanted’ was the highest scoring of affectionate support items, and ‘Someone to have a good time with’ was the highest reported item of PSI.

Table 2. Wave 5 types of support (MOS-SSS)

Support	<i>n</i>	Mean (SD)	<i>M</i>
Affectionate support	43	74.84 (31.54)	8
Someone to love and make you feel wanted	45	4.24 (1.07)	6
Someone who shows you love and affection	44	4.16 (1.16)	7
Someone who hugs you	45	3.91 (1.35)	6
Tangible support	48	64.32 (37.83)	3
Someone to take you to the doctor if you needed it	49	3.82 (1.51)	2
Someone to prepare your meals if you were unable to do it yourself	49	3.55 (1.65)	2
Someone to help you if you were confined to bed	48	3.50 (1.65)	3
Someone to help with daily chores if you were sick	48	3.48 (1.56)	3
Emotional/Informational support	44	62.59 (32.73)	7
Someone you can count on to listen to you when you need to talk	46	3.63 (1.47)	5
Someone to give you good advice about a crisis	46	3.61 (1.37)	5
Someone to confide in or talk to about yourself or your problems	46	3.52 (1.41)	5
Someone whose advice you really want	45	3.51 (1.36)	6
Someone to share your most private worries and fears with	46	3.46 (1.56)	5
Someone to turn to for suggestions about how to deal with a personal problem	46	3.39 (1.41)	5
Someone who understands your problems	46	3.37 (1.40)	5
Someone to give you information to help you understand a situation	46	3.37 (1.44)	5
Positive social interaction	48	57.77 (30.67)	3
Someone to have a good time with	48	3.96 (0.82)	3
Someone to do something enjoyable with	48	3.90 (0.95)	3

Table 2. Wave 5 types of support (MOS-SSS) (*continued*)

Support	<i>n</i>	Mean (SD)	<i>M</i>
Someone to get together with for relaxation	48	3.81 (0.98)	3
Additional item			
Someone to do things with to help you get your mind off things	48	3.69 (1.01)	3

M: Missing cases column in italics; SD: standard deviation. Score range for the four scales 0–100, score range for items in the scales 1–5. This is based on a generic MOS-SSS (Medical Outcomes Study Social Support Survey)

Relationships and support

Total scores (sum of the three relationships) were most affected by epilepsy in Wave 2 (2010) (Table 3). In each Wave partner, family, and friends are listed in the order of lowest effect of epilepsy to the highest. The effects of epilepsy diminished in Wave 4 (2016/7) and even more in Wave 5 (2019/20). Partnerships in Wave 2 were less affected by epilepsy but more so in Waves 4 and 5. Possibly, coping approaches did not work over the long term with partners, compared with family and friends.

Table 3. Effects of epilepsy on supportive relationships over time (Waves 2, 4, and 5)

Wave 2 <i>n</i> Mean (SD)	Wave 4 <i>n</i> Mean (SD)	Wave 5 <i>n</i> Mean (SD)
Partner <i>n</i> = 37 2.64 (3.72)	Family <i>n</i> = 44 2.50 (3.38)	Family <i>n</i> = 39 1.88 (2.74)
Family <i>n</i> = 50 2.90 (3.48)	Friends <i>n</i> = 44 2.88 (3.56)	Friends <i>n</i> = 39 2.31 (3.43)
Friends <i>n</i> = 49 3.32 (3.48)	Partner <i>n</i> = 23 2.90 (3.38)	Partner <i>n</i> = 21 2.54 (3.48)
Total <i>n</i> = 37 30.62 (33.38)	Total <i>n</i> = 23 26.63 (32.48)	Total <i>n</i> = 21 19.05 (28.79)

SD: standard deviation. The total is those who had all three, that is family, friends, and partner. High mean score means greater effect of epilepsy on relationships. Supportive relationships 0–10; scale totals 0–100

Table 3 shows in Wave 2 the effects of epilepsy were less on the relationship with partner compared to the effects of epilepsy on family and friends. This changed over 9 years. In Waves 4 and 5, the effects of epilepsy were less on family and then friends, followed by partners. Differences between the three Waves (over 9 years) for the family were significant (F 4.40, df 2, p 0.016, partial eta squared 0.12), Mauchly's test shows it is reasonable to conclude that the variances of differences are not significantly different [$\chi^2(2)$ 4.43, p 0.109]. Also, differences were significant between Waves for friends (F 3.80, df 2, p 0.027, partial eta squared 0.11). [Mauchly's test $\chi^2(2)$ 5.64, p 0.060, variances are not significantly different]. This means that for family and friends, the effects of epilepsy diminished significantly over the nine-year period (to Wave 5). Differences between the Waves for partners were not significant. Differences were significant between Waves for composite scales of effects of epilepsy on supportive relationships (F 4.69, df 2, p 0.018, partial eta squared 0.25) [Mauchly's test $\chi^2(2)$ 9.73, p 0.008, variances are significantly different]. There were no significant gender differences.

The hypothesis anticipates the negative effects of epilepsy on relationships (partner, family, and friends) will diminish over time (Waves 2, 4, and 5). In Table 4 a minus (–) for change signifies epilepsy having less effect on supportive relationships compared to Wave 2, and a plus (+) means more of an effect compared to Wave 2.

Table 4. Effects of epilepsy on relationships (%)

Variables	Wave 2 (<i>n</i>)	Mean (SD)	Wave 4 (<i>n</i>)	Mean (SD)	Change (Wave 2 to 4)	Wave 5 (<i>n</i>)	Mean (SD)	Change (Wave 2 to 5)
Relationship with partner	37	2.64 (3.72)	23	2.90 (3.38)	+0.26%	21	2.54 (3.48)	–0.1%
Relationships with friends	49	3.32 (3.48)	44	2.88 (3.56)	–0.44%	39	2.31 (3.43)	–1.01%
Relationship with family	50	2.90 (3.48)	44	2.50 (3.38)	–0.40%	39	1.88 (2.74)	–1.02%

+ refers to increase in effect of epilepsy and – decrease in effect of epilepsy. Items are scored 0–10

The reduction of the effect of epilepsy over 9 years was greater for relationships with friends and family than with partners. The hypothesis that it is expected the effects of epilepsy on relationships (partner, family, and friends) will diminish over time (Waves 2, 4, and 5) was not supported.

Results of qualitative analysis of responses

In Wave 2 responses related to a question on the effects of stigmatising events regarding epilepsy. While these were not related to support, most of the responses demonstrated that the impact of a stigmatising encounter was that people isolated themselves to avoid future encounters of this nature. This impacted on the support they might expect and from whom they might expect support.

PWE were likely to avoid encounters with strangers rather than risk facing stigma. There are also places where the risk of stigma is likely to be experienced, including workplaces, schools, and bureaucracies. Some respondents reported never having experienced stigma. One person responded by saying that when he explained to people what might occur and how they could assist, he found that they were generally supportive. This approach suggests someone actively seeking tangible support. In asking for help, issues such as getting help for home chores, help when ill, or in seeing a doctor can be supported (Table 5).

Table 5. Table of responses from people with epilepsy (PWE) demonstrating the value of social support over 9 years

Waves	Quotations demonstrating social support needs
Wave 2. Effects of stigmatising events impacts on seeking social support	<p><i>“People feel you are not able to be left alone or be independent in case you have a seizure.”</i></p> <p><i>“People can judge you because of this condition.”</i></p> <p><i>“When a person or group of people, an employer, a public servant or another person in a position that requires communication with you as someone with a disability that has a direct link to what they feel is a problem.”</i></p>
Wave 4. Emotional/Informational support required from psychologists and counsellors but often difficult to access	<p><i>“Just having such a centre in your community provides a genuine feeling of being in real social contact.”</i></p>
Wave 4. Family support valued	<p><i>“At one time he (son) lived independently with main meals with us until side effects with Epilim kicked in 2016.”</i></p>
Wave 4. Peer support highly valued	<p><i>“Having been involved with the xxxx Adult Support Group since moving to xxxx in 2002, our monthly social activities provide a support base where you share your time together as ‘normal’ people.”</i></p>
Wave 5. Access to specialist epilepsy services valued	<p><i>“At the moment my neurologist is elderly and old-fashioned in knowledge of epilepsy. Having difficulty getting a referral to a more up to date, knowledgeable neurologist.”</i></p>
Wave 5. Regional PWE value state-based epilepsy services	<p><i>“In the early years of my epilepsy when I was very unstable with seizures and loss of licence in the country—the epilepsy organisation was my saviour (it was a very lonely experience). They also offered reading material and get-togethers with other persons like myself.”</i></p> <p><i>“(Epilepsy organisation) promotes current technologies. The glasses with cross-polarised/polar blue have enabled me to leave an abusive husband, drive, not have a seizure since I have been with that husband (2012), work full time, single parent and write a textbook.”</i></p> <p><i>“Getting in contact with the (epilepsy organisation) is what eventually got me diagnosed with epilepsy (and got me the seizure control I have today!!).”</i></p>

Wave 4 participants responded to a question about the types of support people wanted and from whom they wanted support. Participants valued emotional/informational support from psychologists and counsellors. However, those living in regional Australia found these services hard to access. The epilepsy associations in each Australian state thus became an important source of emotional/informational support. When regional services were withdrawn, this was considered a severe loss. Parents of adult children, some of whom had cognitive or intellectual disabilities, answered on their behalf and demonstrated offering a range of supports including tangible ones, such as meals and transport and PSI and affection. Peer support was also strongly valued in regional areas providing both emotional/informational as well as opportunities for PSI. Wave 5 used the MOS-SSS Medical Outcomes Survey and comments boxes provided for additional responses. Once again, the need for emotional/informational support dominated, including the lack of such support in regional Australia. What was most missed was access to specialist epilepsy services.

Once again in regional Australia state-based epilepsy organisations filled some of these gaps, providing telephone support and printed resources. These organisations also provided opportunities for social interaction. The results of Wave 5 are very similar to those of Wave 4. The lack of many responses reflecting social interaction and affectionate support most likely relates to the nature of the survey rather than these forms of support being undervalued. It is likely that respondents, as members of families simply experience these forms of support as part of their lives, while the need and, at times absence, of emotional/informational support stands out.

Discussion

The quantitative component of the study showed that the effects of epilepsy on supportive relationships diminished over time except for partnerships. These relationships (family and friends) were less affected in Wave 4 and even less in Wave 5. The study also showed that PWE received affection the most. It appeared that coping with the effects of epilepsy applied to family and friendships over time, as after 9 years the effects of epilepsy had diminished substantially.

Wave 2 clearly demonstrates that stigma plays an important part in where PWE seek support. This is from partners and family members, suggesting an avoidance of depending on support from broader community interactions. When available, PSI was valued but was confined to meet-ups with other PWE. The qualitative analysis supports the importance of affectionate support, while demonstrating that the demand for emotional/interactional remained a strong and unsatisfied need across the nine years. The transformative potential of emotional/informational support suggests that access to it would assist in building PSI and addressing social isolation.

The results show that in the Australian context, social support for PWE improved over time as other family and friends were less affected by epilepsy. However, for partnerships, the effects of epilepsy did not change. In Australia, there is relatively less emphasis on extended families and therefore support for PWE in countries where there are extended families may be different. Also, in Australia, there is good support from epilepsy organisations, and this may enhance the longer-term support and coping approaches of other family and friends. Stigma requires mitigation to reduce harmful effects. Australia is like many countries where support for stigma needs to be improved.

The quantitative analysis of the panel study focussed on the hypothesis: it is expected the effects of epilepsy on relationships (partner, family, and friends) will diminish over time (Waves 2–5). It was not supported. Our analysis showed that partnerships did not change substantially over the nine years, the effects of epilepsy on family and friends diminished strongly. Manacheril et al. [18] state a longer lead time in coping with negative experiences has an effect on QoL. In terms of stress, adjustment and coping the current study found that several supportive relationships for PWE were important in adapting/coping with the demands of epilepsy.

The quantitative results on types of support experiences by PWE in the current study show that affectionate support was the most evident while PSI was the least sourced. The extent of affectionate support is supported by the findings across all Waves of the robustness of support relationships (partner, family, and friends) in the context of reducing negative outcomes of epilepsy. Social support helps improve self-management, according to Walker et al. [3]. They found in qualitative research with 22 people that the main sources of support were spouses and parents. Later qualitative analysis in the current paper shows a greater need amongst PWE for emotional/informational support. Spouses and parents helped PWE through self-management [3]. Support for self-management occurred along a continuum and seizure control had an important role in PWE experience of support.

Lu and Elliott [4] found that poor social support is linked with poor mental health. This is through activity limitations as a result of epilepsy and inadequate social/emotional support. The negative effects of social support were when the receiver of that support felt uncomfortable or unwanted [5]. Poor social support was associated with depressive symptoms and that was stronger in those with lower income.

According to Gesselman et al. [7], intimate interpersonal relationships were both challenging but important to PWE. They have been linked to increased well-being and self-management, including positive QoL, mortality, and control of seizures. Zhong et al. [12] reported on their study in China that PWE who were married and those in employment had a higher level of social support. Schneidre [22] in an earlier qualitative study focussed on the outcomes of disabilities such as epilepsy for responsibility in everyday relationships and how this affects PWE's thoughts and feelings about themselves.

Charyton et al. [9] maintained social support was related to QoL. They found in their US study that PWE with low levels of affectionate support reported fair to poor self-rated health. Zhong et al. [12] outlined that lack of social support affected the QoL of PWE. Other studies [8, 10, 11] also found low social support a significant predictor of poor QoL.

Mehta et al. [23] found in female, PWE in India, that low-income levels contributed to increased stress, poorer coping, and reduced family functioning. A Turkish study showed that PWE employed emotion focussed coping strategies with their epilepsy, religion being the foremost [24].

Limitations

The study has relatively small numbers ($n = 51$). Larger numbers would have enhanced the analysis. Not all written responses were amenable to qualitative analysis as some responses were ambiguous or single-word answers. Another limitation relates to the lack of medical data for each of the panel members. While clinical improvements are certainly taking place, there are still people whose epilepsy remains intractable and/or unpredictable, and stigma continues to be experienced even by those who have well controlled epilepsy.

We demonstrated changes in people's support needs over time, within a social and cultural context. We applied MOS-SSS as an analytical tool to Waves 2, 4, and 5. In Wave 2 responses to stigmatising events, stigma itself being part of culture, demonstrated that avoidance of possibly unsupportive events and situations was employed by PWE, and support to cope with epilepsy was sought from health professionals and epilepsy associations, where stigma was less likely. This became the baseline on which the longitudinal design was able to build a social context of change in support over Waves 4 and 5. It is notable that coping requires a social context where PWE can feel "normal" as one person termed it. Hence, the value of peer support and seeking social interaction with other PWE.

MOS-SSS was developed to perform with longitudinal data [19], and it provided a framework for qualitative analysis as well as the ability to analyse changes in social context. The social context played a role such as improved educational status, stable relations with partners and family, and improved incomes. For PWE, the MOS scales combine with understanding of the influence of epilepsy on important social relationships, and they give a clearer picture of the nexus of the condition and its impact on the lives of PWE.

Conclusions

In relation to the role of different types of support and the resilience of supportive relationships for PWE, the concept of social construction is central. Support and relationships are important to all, but have a significant impact on PWE, in helping shape the self-concept. Our research has shown that over time (for 9 years), people appear to cope in their relationships affected by epilepsy. Affection may be most evident in the context of supportive relationships. PSI may be difficult for PWE to undertake. Peer support groups offer a safe context in which to model social interaction before participating in the world outside of epilepsy.

Stigma has a strong negative impact on PWE and calls on emotional/informational support, some of which come from health practitioners (such as psychologists and counsellors) and epilepsy-specific organisations. The milieu of PWE such as partner, family, friends, and social circle needs to have an awareness of the coping and adjustments required for PWE to adapt to the demands of epilepsy.

Abbreviations

AELS: Australian Epilepsy Longitudinal Study

MOS-SSS: Medical Outcomes Study Social Support Survey

PSI: positive social interaction

PWE: people with epilepsy

QoL: Quality of Life

Declarations

Author contributions

CW and CLP: Conceptualization, Investigation, Writing—original draft, Writing—review & editing. Both authors read and approved the submitted version.

Conflicts of interest

The authors declare they have no conflicts of interest.

Ethical approval

The ethics clearance was gained by Deakin University Australia (HREC 2013-011).

Consent to participate

This is a panel study consisting of the same people from Waves 2 (2010), 4 (2016/7) and 5 (2019/20). Participants are recruited from the Australian Epilepsy Research Register (AERR) which commenced in 2006. Informed consent was gained from participants.

Consent to publication

All participants gave their permission for their data to be published.

Availability of data and materials

Data is protected by ethics requirements and is not available, but the authors are willing to answer readers' reasonable questions.

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