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Reported service needs at diagnosis of epilepsy and implications for quality of life

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ABSTRACT

Aim: This paper reports on contributing factors to Quality of Life (QoL) in an Australian community sample of people with epilepsy (PWE).
Method: Three hundred and ninety-three respondents or 29.6% of people on the Australian Epilepsy Research Register participated in Wave 4 of a longitudinal survey. A quantitative analysis was undertaken and a qualitative investigation examined open-ended responses by 44 PWE on the support services that they received following diagnosis of epilepsy.
Results: Total Quality of Life in Epilepsy-31 Items (QOLIE-31) score for the community-based sample was 55.99 (SD 19.85) [Range 6.34–96.20]. Age, paid employment, seizure frequency, number of antiepileptic drugs (AEDs), and perceived prosperity had significant impacts on QoL. In addition, use of support services showed that availability of a first seizure clinic, accurate information on support services and peer support were associated with the highest QoL. A qualitative investigation revealed that on first diagnosis, a lack of information was the main theme. Furthermore, PWE reported a lack of understanding of available supports by a range of health professionals, schools, and in the general community.
Discussion: Psychosocial factors were important in explaining QoL, and the positive effects of first seizure clinics, accurate information on support services, and of peer support have been confirmed in the literature. The lack of knowledge of support services on being diagnosed with epilepsy is a problem evident in the community and pathways are required to support people dealing with their epilepsy.
Conclusion: More emphasis is needed in providing availability of supports to enhance the future wellbeing and QoL of people when epilepsy is diagnosed.

1. Background

Living with epilepsy can have a marked impact on an individual's quality of life (QoL) and is detrimentally impacted by poorer epilepsy management and worse psychosocial functioning. In order to help promote better QoL for people with epilepsy (PWE), there is a clear role for services that can provide PWE with information and support to better self-manage and self-advocate. There is, however, relatively less information in the literature on the perspectives of PWE on the types of support services that they feel would be beneficial and how this may relate to QoL. This was therefore the overarching aim of the current study.

A wealth of research to date has examined the medical, psychological, and social factors that can impact QoL. Key factors that have consistently emerged from this research include seizure frequency and severity, the presence of psychiatric comorbidities, such as, anxiety and depression, and social factors, such as, stigma and discrimination [1–8]. However, it is also important to understand the psychosocial factors that affect QoL for PWE [9].

Psychosocial factors that have been suggested to play a role in boosting QoL have included resilience and self-mastery [10]. Importantly, factors such as self-mastery, self-advocacy, and self-management can be improved by providing patients with better information and

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support [11,12]. One qualitative study from South Africa examining patient experiences of their treatment and care, however, found a perceived lack of empathy and interest in their experiences beyond seizure control [13]. While support services are available for PWE through the Australian health system and community epilepsy associations, little is known about which services PWE access, and their value in improving QoL. Increased understanding of the role of support services will assist in better allocation of resources to support PWE.

In order to better understand services that may be beneficial, and how these relate to QoL, we therefore set out to examine what services PWE felt would have been beneficial early in the treatment journeys. We also examined QoL using the Quality of Life in Epilepsy-31 Items (QOLIE-31), and investigated the nature of support perceived and QoL in a self-selecting community sample of PWE in Australia. In this way, we hope to build up a strong profile and understanding of the use of supports and services for PWE in Australia.

2. Methods

2.1. Participants

The 2016/17 Australian Epilepsy Longitudinal Survey (AELS) was conducted using the Australian Epilepsy Research Register (AERR). The AERR is an Australian-wide research register run by the Epilepsy Foundation, which is open to adults (≥18 years) who have epilepsy as well as the family, carers, and friends of PWE. As part of the AELS, participants are sent survey 'Waves' approximately every three years. Participation is voluntary.

Ethics approval was gained from Deakin University Human Ethics (2013 – 011), and all participants gave informed consent.

This study represents an analysis of Wave 4 (2016/17) of the AELS, following previous Waves in 2006, 2010, and 2013. Waves 2 to 3 have been reported on elsewhere [14–17].

2.2. Measures

A questionnaire was distributed to participants of the AERR, either via mail or online in 2016/17. Information was obtained on sociodemographics, epilepsy diagnosis, and seizure information, as well as participants' perspectives on living with epilepsy. A particular focus for Wave 4 was on including open-ended questions on participants' experiences of utilizing epilepsy services and equipment. Of relevance to the current study was the question, "What services did you need when first diagnosed with epilepsy?"

For the purposes of the current study, participant answers to QOLIE-31 were used [18]. The overall QOLIE-31 and subscales have been found to demonstrate good internal consistency and test–retest reliability [19]. Two questions were used to assess the presence of symptoms relating to anxiety ("Have you, in relation to your epilepsy, felt anxious about the future, racing thoughts, heart palpitations?") and depression ("In relation to your epilepsy have you felt sad, helpless, worthless?")

Quantitative analyses were undertaken with the statistical package SPSS Version 24 (IBM Corp. 2016, NY). Frequencies, *t*-tests, and one-way analysis of variance (ANOVA) were used to examine between-group differences in QOLIE-31 scores and have been presented with effect sizes (Cohen's *d* and partial eta squared).

2.3. Qualitative analysis

A total of 44 open-ended comments were received to the question "What services did you need when first diagnosed with epilepsy?" A thematic analysis approach was chosen to analyze these responses. This involved line-by-line coding of responses to identify emerging themes. Themes are then strengthened through ongoing comparison and identification of patterns across the data. Responses were initially coded by one researcher (CW) and confirmed through consensus with CP and HC.

3. Results

For Wave 4, there were 393 respondents from the AERR, which consists of 1328 people, resulting in a 29.6% response rate. Average age of respondents was 42.02 years (SD = 17.3), range 1–83 years (Table 1). The majority of participants were female (67%), lived in urban areas (67%), and almost half were currently employed (47.3%).

3.1. Quality of life

The mean overall QOLIE-31 score was 55.99 (SD = 19.85). The highest mean score was found for the QoL subscale (M = 65.12, SD = 19.19), and the lowest for the Energy subscale (M = 41.06, SD = 23.40). A correlation matrix of all properties of the QOLIE-31 is shown in Table 2. All correlations were significant at $p < .01$.

There was a significant relationship between age and overall QOLIE-31 score, with those 65 years and older reporting higher QoL (Table 3). Employment status was assessed in Wave 4 for those participants 17 years and older; those who were employed had a significantly higher QoL than those without employment. Those who reported belonging to 'Poor' or 'Very Poor' economic brackets had lower QoL compared with those who considered themselves to be Prosperous or Very Comfortable. Poorer QoL was also significantly associated with more frequent seizures over the past 12 months and with polytherapy.

In relation to anxiety, there was a significant difference in QoL between those who endorsed symptoms of anxiety (n = 194, QoL = 50.46, SD = 17.88) and those who did not (n = 107, QoL = 69.12, SD = 16.62) ($t = 8.88$, df = 299, $p = .000$, Cohen's d = 1.08, *large effect*). There was also a significant difference in QoL between those who reported symptoms of depression (n = 216, QoL = 51.53, SD = 18.17) and those who did not (n = 84, QoL = 71.19, SD = 15.66) ($t = 8.74$, df = 298, $p = .000$, Cohen's d = 1.16, *large effect*).

3.2. Use of support services

Table 4 shows QOLIE-31 scores for medical and psychosocial supports, according to how satisfied participants were with their

Table 1
Demographic characteristics.

Item	Level	n (%)
Gender	Female	258 (67.0%)
	Male	126 (32.7%)
	Intersex	1 (0.3%)
Education	Up to year 10	78 (21.0%)
	Years 11–12	68 (18.3%)
	TAFE/Trade	67 (18.0%)
	Diploma	41 (11.0%)
	University degree or higher	118 (31.7%)
Employment[a]/status[b]	Employed	176 (47.3%)
	Student	36 (9.7%)
	Retired	35 (9.4%)
Current location	Urban	254 (67%)
	Rural	114 (31.0%)
Living arrangements	Live alone	65 (17.6%)
	Live with partner and/or children	182 (49.2%)
	Live with other family members	84 (22.7%)
	Live with friends/shared accommodation	21 (5.7%)

[a] Employment 17 years and older.
[b] % not /100.

Table 2
Quality of life properties.

QOLIE 31	n	Mean (S D) [95%CI] [Range]	Total	Seizure worry	Overall QoL	Emotional wellbeing	Energy	Cognitive	Medication effects
Total	342	55.99 (19.85) [53.87, 58.01] {6.34. 96.20}							
Seizure worry	345	57.67 (30.19) [54.47, 60.86] {00, 100}	0.66						
Overall QoL	348	65.12 (19.19) [63.09, 67.16] {00, 100}	0.76	0.43					
Emotional wellbeing	346	60.46 (21.41) [57.93, 62.47] {00, 100}	0.71	0.40	0.65				
Energy	346	41.06 (23.40) [38.43, 43.41] {00, 100}	0.69	0.38	0.58	0.63			
Cognitive	345	53.99 (26.76) [51.04, 56.72] {00, 100}	0.83	0.43	0.52	0.45	0.43		
Medication effects	344	47.99 (32.99) [44.99, 51.48] {00, 100}	0.60	0.53	0.43	0.42	0.41	0.41	
Social Function	347	58.77 (29.83) [55.58, 61.87] {00, 100}	0.86	0.58	0.62	0.46	0.48	0.63	0.51

current level of access to, and quality of, a range of support services (assessed using Kruskal–Wallis tests). The table reports the numbers of people, and the QOLIE-31 scores for each category. It should be noted for every support there were in excess of 100 missing cases.

The results show that those very satisfied with access to 'a first seizure clinic' (i.e., a clinic for the comprehensive care of patients with recent onset of episodes that are suspected to be seizures) had the highest QoL of all people accessing supports, followed by access to 'accurate information on support services' then 'peer support'. Those with the lowest QoL for being very satisfied were those receiving 'occupational therapy'. In general, patients who reported that they did not need to access support services reported significantly higher QoL compared to those who did need the supports listed in Table 4, with the exception of 'a first seizure clinic.' For the remaining supports (excluding 'dietician,' physiotherapist,' and 'General Practitioner'),

Table 3
Relationship between overall QOLIE-31 score and demographic factors.

Scale/components	N (%)	Mean (SD) [95% CI]	*p* value (effect size)
Age	341		
Under 18	21 (6.2)	55.69 (21.60) [47.31, 64.06]	.002 ($\eta^2 = 0.043$)
18–42	143 (41.9)	53.21 (18.59) [50.00, 56.43]	Small to medium
43–64	149 (43.7)	56.22 (20.14) [53.07, 59.368]	
65 and older	28 (8.2)	68.83 (19.29) [61.59, 76.10]	
Gender	342		
Female	227 (66.4)	55.41 (20.19) [52.77, 58.05]	ns Cohen's d 0.01
Male	115 (33.6)	57.13 (19.18) [53.59, 60.67]	Trivial
Highest level of education	339		
Up to Year 10	70 (20.6)	54.53 (19.38) [49.91, 59.15]	ns ($\eta^2 = 0.02$)
Years 11–12 (HSC)	61 (18.0)	57.42 (16.96) [53.07, 61.76]	Trivial
TAFE/Trade	61 (18.0)	55.02 (19.02) [49.92, 60.12]	
Diploma	38 (11.2)	49.73 (21.99) [42.51, 56.96]	
University degree or higher	109 (35.1)	59.02 (20.37) [51.15, 62.88]	
Employment status[a]	321		
Not employed	162 (50.5)	52.25 (20.32) [49.10, 55.41]	.001 Cohen's d 0.38
Employed	159 (49.5)	59.62 (18.49) [56.72, 62.51]	Small to medium
Self-reported prosperity	337		
Very poor	9 (2.7)	48.46 (17.45) [3505, 61.87]	.000 ($\eta^2 = 0.104$)
Poor	20 (5.9)	38.67 (18.51) [30.01, 47.34]	Medium to large
Just getting along	119 (40.9)	52.41 (18.94) [48.97, 55.84]	
Reasonably comfortable	138 (46.2)	58.59 (19.07) [55.38, 61.80]	
Very comfortable	43 (12.8)	63.70(16.64) [58.59, 68.82]	
Prosperous	8 (2.7)	72.54 (26.57) [50.33, 94.74]	
Years since diagnosis	337		
0–3	24 (7.1)	55.07 (25.45) [44.32, 65.81]	ns ($\eta^2 = 0.007$)
4–16	113 (33.5)	54.19 (20.66) [50.34, 58.04]	Trivial
17–32	103 (30.6)	55.83 (16.25) [52.66, 59.01]	
33 or more	97 (28.8)	58.30 (20.87) [54.09, 62.51]	
Seizures over past 12 months	338		
None	143 (42.3)	66.69 (18.33) [63.65, 69.71]	.000 ($\eta^2 = 0.25$)
Less than 1 per month	92 (27.2)	52.34 (16.74) [48.87, 55.81]	Large
1 or more per month	52 (15.4)	48.70 (16.79) [44.02, 53.37]	
1 or more per week	51 (15.1)	40.10 (15.56) [35.72, 44.47]	
Number of epilepsy drugs	340		
None	22 (6.5)	69.00 (18.70) [60.71, 77.28]	.000 ($\eta^2 = 0.086$)
1	126 (37.0)	59.80 (20.76) [56.14, 63.46]	Medium to large
2	96 (28.2)	52.78(18.56) [49.01, 56.53]	
3	63 (18.5)	53.25 (17.73) [46.78, 57.71]	
4	20 (5.9)	44.49 (16.84) [36.61, 52.37]	
5	7 (2.0)	39.91(9.48) [31.13, 48.67]	
6 or more	8 (2.4)	58.02 (21.94) [35.00, 81.01]	

Note. HSC = High school certificate; TAFE = Technical and Further Education.
[a] 17 years and older.

there was an incremental increase in QoL from not satisfied with the service to being very satisfied.

3.3. Qualitative analysis of services participants identified as helpful on diagnosis

When asked which specific services participants were most in need of after first diagnosis, the five most common responses were General Practitioner (GP) (n = 198), counselor (n = 97), peer support (n = 89), a pediatric neurologist (n = 82), and a first seizure clinic (n = 77).

The primary theme that emerged from qualitative analysis of participant responses related to a perceived lack of information and access to services and support at the time of diagnosis. For some participants, this had the potential to result in notable and ongoing distress. Others commented on the general lack of understanding that they themselves had, as well as being met with a lack of understanding from health professionals, schools, and the community.

Lack of information at the time of diagnosis commonly related to difficulty accessing specialist epilepsy services, particularly epileptologists/neurologists, but also allied health professionals to manage comorbid anxiety/depression.

> "Neurologists specialising in epilepsy should be more heavily advertised, or GPs should be made aware of referring patients to neurologists with specialist knowledge.""The percentage of depression and anxiety is so high in people with epilepsy, we need to know that support in that area is available."

In many of these cases, respondents relied on nonspecialists, including GPs and pediatricians. Delays in getting appropriate diagnoses and treatment could prove detrimental, resulting in poor seizure management and increased distress for the participant.

> "I was given the wrong medication that I found out years later made my specific type of epilepsy [JME] worse and actually exacerbated my seizures."

> "When I got epilepsy, my parents didn't get medical assistance whatsoever and I just kept having seizures. Finally I saw a

Table 4
Psychosocial and clinical supports and QoL.

	Not required	Not satisfied	Slightly satisfied	Very satisfied
Psychologist (n = 252)***	n = 163 (64.7%)	n = 37 (14.7%)	n = 30 (11.9%)	n = 22 (8.7%)
QoL	63.04 (SD = 18.22)	41.48 (SD = 1.23)	49.82 (SD = 15.73)	51.50 (SD = 18.61)
Psychiatrist (n = 252)***	n = 195 (78.2%)	n = 27 (10.7%)	n = 11 (4.4%)	n = 19 (7.5%)
QoL	60.13 (SD = 18.75)	41.07 (SD = 19.56)	48.88 (SD = 12.40)	49.36 (SD = 20.48)
Case worker (n = 247)***	n = 197 (79.8%)	n = 30 (12.1%)	n = 8 (3.2%)	n = 12 (4.9%)
QoL	60.88 (SD = 18.76)	42.61 (SD = 16.18)	46.20 (SD = 14.13)	54.33 (SD = 13.72)
Counselor (n = 253)***	n = 165 (65.2%)	n = 36 (14.2%)	n = 27 (10.7%)	n = 25 (9.9%)
QoL	62.85 (SD = 18.18)	43.91 (SD = 16.17)	45.14 (SD = 15.35)	52.13 (SD = 20.12)
Occupational therapist (n = 242)**	n = 196 (81.0%)	n = 25 (10.3%)	n = 9 (3.7%)	n = 12 (5.0%)
QoL	59.76 (SD = 19.14)	45.15 (SD = 16.62)	48.14 (SD = 24.61)	49.11 (SD = 14.53)
Physiotherapist (n = 243)***	n = 189 (77.8%)	n = 24 (9.9%)	n = 15 (6.2%)	n = 15 (6.2%)
QoL	60.61 (SD = 18.69)	44.61 (SD = 16.72)	48.71 (SD = 17.74)	48.70 (SD = 20.66)
Speech pathologist (n = 249)*	n = 218 (87.6%)	n = 14 (5.6%)	n = 9 (3.6%)	n = 8 (3.2%)
QoL	58.24 (SD = 18.80)	43.22 (SD = 22.05)	49.66 (SD = 18.90)	51.03 (SD = 23.10)
Massage therapist (n = 241)***	n = 187 (77.6%)	n = 31 (12.9%)	n = 7 (2.9%)	n = 16 (6.6%)
QoL	60.18 (SD = 19.27)	44.35 (SD = 16.68)	52.53 (SD = 16.81)	52.59 (SD = 16.06)
Peer support (n = 261)***	n = 123 (7.1%)	n = 69 (26.4%)	n = 32 (12.3%)	n = 30 (11.5%)
QoL	64.39 (SD = 17.25)	47.32 (SD = 21.82)	54.83 (SD = 16.14)	59.37 (SD = 13.52)
Dietitian (n = 256)***	n = 184 (71.9%)	n = 38 (14.8%)	n = 19 (7.4%)	n = 15 (5.9%)
QoL	60.59 (SD = 18.46)	47.93 (SD = 16.58)	44.53 (SD = 18.93)	52.53 (SD = 19.99)
Access to first seizure clinic (n = 232)***	n = 161 (69.4%)	n = 42 (18.1%)	n = 13 (5.6%)	n = 16 (6.9%)
QoL	60.93 (SD = 18.09)	42.04 (SD = 17.49)	45.53 (SD = 16.09)	67.69 (SD = 19.65)
General Practitioner (n = 292)***	n = 40 (13.7%)	n = 21 (7.2%)	n = 64 (21.9%)	n = 167 (57.2%)
QoL	67.45 (SD = 16.81)	50.00 (SD = 22.04)	49.34 (SD = 18.44)	58.87 (SD = 18.74)
Epileptologist (n = 243)***	n = 136 (56.0%)	n = 36 (14.8%)	n = 19 (7.8%)	n = 52 (21.4%)
QoL	62.33 (SD = 17.68)	44.43 (SD = 21.34)	49.81 (SD = 16.02)	56.96 (SD = 17.88)
Neurologist (n = 277)***	n = 47 (17.0%)	n = 38 (13.7%)	n = 61 (22.0%)	n = 131 (47.3%)
QoL	67.99 (SD = 17.71)	50.44 (SD = 21.60)	50.88 (SD = 17.07)	58.63 (SD = 18.90)
Accurate information on support services (n = 266)***	n = 67 (25.2%)	n = 92 (34.6%)	n = 53 (19.9%)	n = 54 (20.3%)
QoL	67.23 (SD = 15.54))	49.55 (SD = 20.42)	54.08 (SD = 18.87)	59.62 (SD = 17.47)

Note. SD = Standard deviation.
* $p < .05$.
** $p < .01$.
*** $p < .001$.

neurologist, but I suffered quite [a bit] and everything was hidden from me."

It also meant that the participants themselves lacked a complete understanding of the nature of and best ways to manage their epilepsy.

"My diagnosis did not seem definite. I foolishly thought I could control my symptoms/medication use/skimp on medications through lifestyle means."

Only two respondents described how they were provided with information – one via pamphlet and the other a website – with no mention of further follow up. Likely as a result of the lack of information, many respondents felt that better training is needed for general health professionals about epilepsy, as well as the other support services available.

"More education needed in the health professions in which I work."

"Even disability services officers not aware of the above [supports available]."

This had the potential to result in uncertainty and distress, not just for the PWE, but also potentially for family members, who were also felt to need more support and information.

[What was the support needed?] "Anyone that could answer my questions. I was so frightened."

"Family's inability to cope and refusal to follow medical advice more of a problem than dealing with seizures."

The possible ongoing impact of this lack of diagnosis was evident in respondents' expression of resentment at having to find their own way.

"Neck is stuffed, spine is stuffed, kidneys failing, no memory for most of my life prior to 2002."

"I haven't heard [of] or been offered any of these things ever so it's very hard to answer. That is why they are all unsatisfied."

Access to specialists was impeded for some respondents by geographical and/or financial barriers.

"When I was diagnosed at 16 my family couldn't afford a private specialist so we had to go through the public hospital where I didn't even see a neurologist."

"For where I live, there's very little, or rather nothing is here. Except for a plane trip to Perth — about 2,000 km away! It's almost an [unknown] subject of concern up here."

Misunderstandings of epilepsy were evident beyond the health profession, and respondents felt as though more information was needed for the wider community, including friends and family, but particularly noted for schools. This had the potential to result in the experience of felt and/or enacted stigma, and detrimentally impacted their educational experience.

"Even my friends when we go out socially just don't get it that I can't cope being out late."

"I was […] in Wangaratta, Victoria. I got the basic needs and put in a lower class in school because my brain wasn't working properly. Joke! It did happen"

That there had been little change in access to services over the timeframe was also evident. There was also a general belief that services and supports were less available "back then," i.e., when the participant's epilepsy was diagnosed. Inspection of participant ages showed that this was a consistent perception over time, suggesting little improvement in directing patients toward information and support services over the past 50 years.

"Most non-existent when first diagnosed – **1950**!"

"Diagnosed 37 years ago [**1979**] – nothing available."

"At 16 [**2005**], none of the other services were made available or encouraged."

Preferable scenarios described by respondents included having more access to information about epilepsy itself, their own diagnosis and services, particularly early after epilepsy onset. This information was a key to taking control, and could be gained through better access to specialists, particularly neurologists, but also through more information about other possible support services available. Personal and family counseling was listed as helpful and to a smaller degree, as were support groups and increased social support in general.

3.4. Quality of life in relation to participant responses

Of the 44 responses received, 12 participants did not complete the QOLIE-31. Of the remaining 32, 15 were above average or very high QoL; three had average QoL, and 14 were below or very below average QoL. Regardless of QOLIE-31 scores, all respondents reported problems related to access to support and information. Consistent with the finding of an association between self-reported income level and QoL, those reporting difficulty accessing specialists due to finances/geographical hurdles also reported below average QoL.

4. Discussion

The current study provides a profile of a community cohort of PWE living in Australia with regard to QoL and use of support services. The results of our study are largely consistent with the literature in terms of identifying factors that adversely impact QoL. In the current study, our Australian community sample reported a group mean QoL of 55.99 (SD = 19.85). This is slightly lower than the global mean of 59.8 (SD = 8.0) [20] and that of a UK sample (M = 62, SD = 15.6) [10], albeit not a significant difference. The lower score may be due to the self-selecting nature of our sample and the relatively high rate of symptoms of anxiety (64%) and depression (72%) reported in our cohort (although it should be noted that these symptoms were assessed by means of a single question). Consistent with previous literature, however, we found that seizure frequency, number of AEDs, age, employment, level of perceived prosperity, and the presence of mood symptoms impacted participant QoL [6]. The strong effect of perceived wealth or prosperity found here is relatively less reported on in the literature; however, this is consistent with a recent meta-analysis examining QoL across low-, medium-, and high-income countries [20].

The results provide valuable insights into the perspectives of a community cohort of people living with epilepsy on the supports and services available to them, and what they perceive would have been of most benefit when they had their first diagnosis. A key finding of the current study arose from the qualitative analysis, which pointed toward the absence of support services as something that can prompt feelings of distress, anxiety, and difficulty in coping and managing one's epilepsy. However, results suggest that the range of supports available were not considered necessary by two-thirds or more of those who responded. Generally, those not considering such services as necessary had a higher QoL. The main exception to this was 'access to a first seizure clinic' where those very satisfied had a higher QoL than those who did not require this service, followed by 'access to accurate

information about support services,' and gaining 'peer support.' Those who did take advantage of services and were very satisfied with them reported a higher QoL than those who took advantage of the services and were less satisfied with them. While inconclusive, one explanation is that participants who did not seek out extra supports may have fewer comorbidities or are better able to self-manage their epilepsy, reducing its impact on their QoL. Alternatively, they might have already had access to other support, while the smaller number who took advantage of them did so because there were no other such supports in place. The differences between being satisfied or not with services offered may relate to the quality of services available.

Participants considered that they would have benefited from more information at diagnosis about epilepsy itself and the ranges of services available to them. This is a consistently reported need in much of the literature where it is argued that good information assists with better management and self-management and overall QoL [21–23]. In this research, there is evidence that both access to first seizure clinics and information at the time of diagnosis was considered important in improving QoL both by those who lacked it and those who received it. Accompanying this is the need for access to specialists, especially neurologists, since primary care physicians were identified as not being sources of good information about epilepsy or available supports. However, only having access to primary care was widely reported. This is consistent with other studies, for example, the US National Health Interview Survey 2010 and 2013 reported that 36% of PWE only had access to this source of clinical care in the 12 months prior to the survey [24].

4.1. Evidence of psychological distress

Poor access to information around the time of diagnosis had the potential to prompt notable anxiety, which some participants reported could continue for many years. The impact of continuing anxiety on QoL may be further compounded in some cases by continuing seizure anxiety, unemployment, low incomes, and poor educational attainment. Participants expressed strong views that more information and support would have assisted to allay such anxiety.

It is important to note that the qualitative results indicated a perceived lack of service availability at the time of diagnosis. This perception was ongoing, and there was little change over time in the information available following diagnosis.

While there is evidence that information, education, peer support, self-management, and other services have increased incrementally from the 1950s onwards [23,25], these responses suggest that the pathways to accessing such information about services have not improved. In the survey, people were provided with space to record their experiences of services that they now consider to have supported them on their first diagnosis of epilepsy.

4.2. Improving access to coordinated care

These responses are retrospective and based on experiences of living with epilepsy, sometimes over many decades. In this regard, they offer significant indications for the need to improve access to support services [26]. They echo the US-based publication Epilepsy Across the Spectrum: Promoting Health and Understanding:

> "Improving the lives of people with epilepsy and their families involves sustained and coordinated efforts, ranging from increasing the understanding of the biomedical mechanisms of the disorder to enhancing clinical treatment and community services. […] A patient-centered approach to health care is needed with an emphasis on the coordination of epilepsy-specific services with care for comorbidities and with links to community services." p 162 [21]

Both the evidence of continuing psychological distress and persisting perceptions that support was not available at time of diagnosis suggests that PWE may benefit from earlier referrals to support services. Key to this would be the promotion of better pathways to support services through greater cooperation between primary and tertiary health services and community organizations [26–28]. For PWE in Australia, there will also be geographical barriers to information and care, which means that alternative methods of service delivery should be considered such as telehealth and other digital solutions [29].

5. Strengths and limitations

This study draws on the responses of a large self-selected community cohort, which is unique in the literature on Australian PWE. Furthermore, the use of a mixed methods approach ensures a person-centered focus for our research, as well as supporting findings through multiple forms of data. It should be noted, however, that the self-selecting nature of our sample may represent a potential drawback, as this population appears to have a slightly lower QoL than would be expected for a high-income country like Australia. This may suggest that our sample is slightly weighted toward those of lower socioeconomic status. Finally, the open-ended questions also required participants to reflect back over a long period of time in order to recall their experiences of diagnosis. Given the consistency of participant responses and significance of this event, it was felt that any loss of detail in recalling this event did not adversely affect our results.

6. Conclusion

In order to better understand what services may be beneficial and how these relate to QoL, we set out to examine what services PWE felt would have been beneficial early in the treatment journeys. Our article suggests that first seizure clinics, accurate information on supports, and peer support will be of benefit to those with poorer QoL. It also emphasized the need for comprehensive early information about the availability of support services as well as better access to them. Further research is required to fully assess which support services are of most benefit to which PWE.

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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 report is consistent with those guidelines.

Note: The questionnaire for this study is available by contacting the corresponding author Dr. Chris Peterson c.peterson@latrobe.edu.au

Declaration of competing interest

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

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