



# Reassures Me There Are People Around Who Care about Me: Analyzing Meanings of Support for People with Epilepsy

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## Abstract

**Aims** The study aimed to examine the nature and outcomes of social support for the well-being and quality of life (QoL) of adults with epilepsy.

**Methods** The Australian Epilepsy Longitudinal Survey's 5<sup>th</sup> Wave included the Medical Outcomes Study Modified Social Support Survey on four dimensions of social support and the QOLIE-31. Both numerical data and open-ended responses were analyzed quantitatively and qualitatively. A mixed method was used where quantitative analysis used *t*-tests, analysis of variance and block recursive regression, and qualitative analysis identified themes.

**Results** Three-hundred thirty-two people with epilepsy (PWE) participated. The quantitative component showed that for emotional/informational support being older and living alone were key factors. These as well as household income were important in tangible support. For affectionate support living alone and household income were factors, but only income was a factor for positive social interaction. In addition, only positive social interaction predicted increased QoL. In the qualitative component of the study both positive and negative supports were identified for the emotional/informational supports. Many reported the benefits of having information, although some reported failure to have their needs taken seriously by health professionals or epilepsy associations. Inability to drive was an important feature of negative tangible support as was finding some assistive services unaffordable. Reports of positive social interaction identified being accepted as a person with epilepsy that is the primary concern. Peer support plays a role here.

**Discussion** The findings of factors affecting the four dimensions of support in this study have supported a number of studies. This includes the effects of positive social interaction on QoL. The qualitative analysis supports these results, but it also contributes to deeper understanding of support in the lives of PWE.

## Keywords

- mixed method
- support
- quality of life

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**Conclusion** Social support is a particularly important issue for PWE. The results of this study demonstrate the complexities and benefits of obtaining the appropriate forms of support. This survey took place before the coronavirus disease 2019 pandemic and it may well be that this phenomenon affects PWE's support needs.

## Introduction

Much of the literature on social support in epilepsy starts from the assumption that support is broadly beneficial to improving health and well-being.<sup>1–8</sup> For example, Lu and Elliot<sup>2</sup> studied the relationship between social support and mental health using a community-based survey, hypothesizing that people with epilepsy (PWE) with daily activities limited by seizures and poor social support would report poor mental health. Their research confirmed this but additionally found that people with poor mental health were likely to have poor support. Whatley et al<sup>9</sup> researched the effects of depressive symptoms, stigma, social support on quality of life (QoL) in adults with epilepsy and found that levels of social support were significant predictors of QoL. The article considered that social interactions could contribute to improving QoL and supportive caring also help with following treatment regimens. However, the results only considered the relationship between depression and social support at the most generalized level, so the complexities of social relationships and caring were not fully delineated.

The complex role of social support becomes clear from some of the literature demonstrating that meaningful support may be derived from varying sources and is dependent on context. For example, Unalan et al<sup>10</sup> writing about support in Turkish PWE found that religion was an important support for some who had more than one generalized seizure per month. The authors comment that this finding needs more investigation.

Studies show that the quality (functional dimension) of the relationships is a better predictor of health than the quantity (structural dimension).<sup>11,12</sup> This suggests that measuring support requires nuanced items to capture meanings attributed to it by those requiring or providing support. Gottlieb and Bergen<sup>13</sup> make valuable distinctions among social support, social networks, and social integration. Their aim is to use the distinctions to clarify what is to be measured and how best to undertake those measures. They offer definitions of support-related concepts and most importantly see support residing in the relationship between the giver and receiver. Lee et al<sup>14</sup> distinguished between positive and negative social support. Positive support was instrumental where a person received physical or financial assistance and could be emotional supportive where companionship and intimacy were offered. Negative effects of support were experienced when it was unwanted, made the recipient feel uncomfortable, or was not the support that the person needed. They employed a six-item checklist for both positive and negative support. Other research has used the social experience checklist which has an eight-item checklist for

both the positive and negative.<sup>15</sup> Charyton et al<sup>16</sup> used an abbreviated version of the Medical Outcomes Study Modified Social Support Survey (MOS-SSS) in their research on QoL and social support in 550 PWE taken from a much larger survey. These items covered availability of someone to help with daily chores, someone to relax with, someone to understand problems, and someone to provide affection.

## Methods

The Australian Epilepsy Research Register (AERR) is an Australian-wide research register of the Epilepsy Foundation Australia.<sup>17</sup> It is open to people in Australia with epilepsy, their family, carers and friends, and only records basic demographic information. The majority of registrants reside in Victoria. The register was first established in 2006, the same year that the first Australian Epilepsy Longitudinal Survey (AELS) was distributed. Since then, there have been four additional "waves" (data collections) seeking demographic and psychosocial data from people on the AERR. Each "wave" has approximately half the same questions and half a new set of questions, giving each "wave" a different theme. Demographic and clinical questions are self-report and the same in each "wave," while different sets of questions around QoL, social support, stigma, and other related sets of questions are used. This has allowed for a panel analysis of results (same questions from each "wave") and separate longitudinal cross-sectional analyses of each "wave."

In Wave 4 (2017) of AELS, the new set of questions concentrated on professional support PWE required after diagnosis and access to aids and equipment respondents perceived as helpful to managing activities of daily living.<sup>18</sup> In Wave 5, the survey included the MOS-SSS to explore support in a broader context.

The study reported here is of Wave 5 that was distributed by mail (hard copy) and separately by Survey Monkey to participants comfortable with completing the survey online. In 2019/20, 332 PWE, their family, or paid and unpaid carers completed the survey (generally only if the PWE (person with epilepsy) and were under 18 years of age. The response rate was 25.7%.

The AELS does not involve access to medical records. Clinical information is self-reported. Participation in all survey waves is voluntary and all participants provide informed consent. Ethics approval was gained from Deakin University HREC No:2013-011. A mixed method design (qualitative and quantitative) was chosen as it allows for a more comprehensive and detailed exploration of the experiences of PWE.

## Measures

Topics covered in Wave 5 were sociodemographics, seizure-related variables (type, frequency), QoL, and types of social support. These are discussed in more detail in the following text.

### Quality of Life in Epilepsy

The 31-item QOLIE-31 scale has been used extensively in epilepsy research in investigating level of QoL and the effects of a range of factors on QoL. It comprises seven subscales. The domains are overall QoL, emotional well-being, energy-fatigue, cognitive functioning, medication effects, seizure worry, and social function. The scale(s) have been found to show good internal consistency and test-retest reliability.<sup>19</sup>

### Social Support Scale

Noting the lack of nuanced detail about the role of support beyond the instrumental in Wave 4, the researchers undertook to explore this more fully in Wave 5 of the AELS. On this basis, we chose the MOS-SSS a validated scale.<sup>19</sup>

“Among the tools developed for the assessment of the perception of social support, the Medical Outcomes Study Social Support Survey, MOS-SSS is one of the most widely used internationally.”<sup>20</sup> There are 19 functional support items measuring five social support dimensions: emotional support expressing positive affect, understanding with empathy, and expressions of feelings; informational support including advice, information, and feedback; tangible support providing material aid; positive social interaction (PSI) to have fun with others/another; and affectionate support involving love and affection. “Affectionate support has not been emphasized in the literature as a distinct type of support, but we felt that this type of support would be very beneficial to health outcomes of the chronically ill.”<sup>11</sup> The scale shows internal consistency, and interscale correlations are 0.72 to 0.90. Reliability (Cronbach alpha) of the scales range from 0.91 to 0.97<sup>11</sup>. Alpha ranges for the AELS study are from 0.95 to 0.96 (see ►Table 1).

One item from the RAND Social Support scale (MOS) is missing in our study due to a technical error: item no. 7 in the emotional/informational support scale—“Someone to turn to for suggestions about how to deal with a personal problem.” We have taken the means of the variable before and after (“someone to share your most private worries and fears with”; and “someone who understands your problems”) and the average for Item 7 (mean)=3.32 (standard deviation: 1.35).

The AELS Wave 5 study is compared to MOS<sup>11</sup> on emotional/informational, tangible, affectionate, and PSI support subscales with a view to comparing Cronbach alphas. This indicates that the emotional/informational subscale, having a revised item 7 is sufficiently reliable compared to the MOS scale to justify its inclusion in a social support analysis in the AELS study.

The emotional/informational subscale mean score was 59.6 that was 10.0% lower than the MOS study reported but had a similar Cronbach alpha of 0.96. However, this lower mean score for the AELS study was repeated for positive

**Table 1** Scale means (SD) and Cronbach alphas for the AELS compared to the MOS study

Support subscales	Mean	SD	Alpha
<b>Emotional/informational</b>			
MOS	69.6	25.5	0.96
AELS	59.6	29.4	0.96
<b>Tangible</b>			
MOS	69.8	28.5	0.92
AELS	68.9	33.5	0.95
<b>Affectionate</b>			
MOS	72.7	28.2	0.91
AELS	74.1	31.8	0.96
<b>Positive Social Interaction</b>			
MOS	69.8	26.0	0.94
AELS	61.0	27.6	0.96
<b>Total Scale</b>			
MOS	70.1	24.2	0.97
AELS	64.3	23.4	0.95

Abbreviations: AELS, Australian Epilepsy Longitudinal Survey; MOS, Medical Outcomes Study; SD, standard deviation. MOS Sherbourne and Stewart.<sup>11</sup>

social interaction (61.0, being 8.8% lower than the MOS study with a higher Cronbach alpha of 0.96 compared to 0.94). These two lower subscale scores for AELS are indicative of reduced social capital in the AELS community-based sample. The total scale means were slightly higher compared to the AELS study and Alpha scores slightly higher<sup>11</sup> than in the AELS study.

## Quantitative Analysis

Quantitative analyses were undertaken with the statistical package SPSS Version 27 (IBM Corp. 2019, New York, United States). Frequencies, *t*-tests, analysis of variance (ANOVA), and block recursive regression were undertaken. *t*-tests and ANOVA analyses were undertaken for the sociodemographics of each of the social support subscales, reporting *t*- and *F*-values and *p* scores. Effect sizes (Cohen's *d* and eta squared  $\eta^2$ ) are also reported.

A block recursive regression was also undertaken, with QoL the dependent variable (scored 0–100). Independent variables were age, gender, highest level of education, being in paid employment, average weekly household income, number seizures in the past 12 months, number of epilepsy drugs, and the four social support subscales. Total effects of variables are reported.

## Qualitative Method

Following the MOS-SSS, an open-ended question asked respondents to describe how support helped them. There were 125 responses, with 17 of these excluded from

qualitative analysis as they were short answers (“No”, “Not needed”) with no indication of their specific reference. A further nine responses were removed as they referred to health conditions or past experiences unrelated to epilepsy. The remaining 99 were subjected to thematic analysis. Two researchers (CW and CP) independently coded the responses according to keywords (e.g., “advice”; “fun”; “helpful”; “not helpful”) in the comments. Following this they discussed their results and classified them using the themes provided by the MOS-SSS. Some comments covered more than one thematic area and consequently relate to more than one theme. Considering research that found not all offers of support were helpful or appropriate<sup>14</sup> negative responses were included.

Ninety-nine respondents provided answers. The number of responses (118) is greater as some people provided examples of several types of support.

Positive emotional/informational support occurs when expectations are met and offers hope, and may open up access to new avenues for support or new ways of viewing one’s needs and well-being. Negative emotional/informational support defined here as seeking assistance and finding it inappropriate, inadequate or not meeting expectations. Sometimes negative support experiences are related to the personal manner of the provider.

Tangible support relates to receiving practical assistance. Lack of access to any support due to costs has been reported as negative tangible support since lack of funds is a practical response. Also lack of services is included as negative tangible. Affectionate support relates to closeness or intimacy as an integral part of a relationship. PSI shows that peer support is greatly valued. Organizational names and individuals in examples have been deidentified.

### Missing Data

Overall, there were relatively small numbers of missing data (such as 6 missing from highest level of education). As epilepsy studies are often of smaller samples than the present study, these missing data have a relatively small impact.

## Results

### Participants

Given nonresponders did not give permission to use their data for the current study, we could not compare sociodemographic information for nonrespondents. Information on survey participants can be seen in ►Table 2. Of the respondents, 3 were paid carers, 39 were family members and 17 were other.

## Data Analyzed Quantitatively

### Sociodemographics for the Four Types of Support

►Table 3 shows that gender has no significant associations but generally men report more support than women. Younger people report significantly more emotional and tangible support (each with a small/medium effect size (eta square)).

**Table 2** Sociodemographics

Demographic	Mean, median (SD) range n%	Missing
Age	48.62; 49.0; (15.43); 18-87	
Gender (female)	185 (69.8%)	
(Male)	80 (30.2%)	6
Highest level of education		
Year 12 or lower	81 (31.3%)	
TAFE/Trade	39 (15.0%)	
Tertiary	139 (53.7%)	6
Paid employment	131 (49.8%)	2
How employed		1
Full-time employed	73 (27.7%)	
Part-time employed	37 (14.0%)	
Casually employed	22 (8.3%)	
Retired	36 (13.6%)	
Studying	12 (4.5%)	
Unable to work due to epilepsy	35 (13.2%)	
Seeking paid employment	24 (9.1%)	
Homemaker	19 (7.2%)	
State Victoria	149 (70.6%)	

Abbreviations: SD, standard deviation; TAFE, Technical and Further Education

Highest level of education made no significant difference on all types of support. People living with other family compared to those with partners and/or children, live on their own or are in shared accommodation, and have significantly more supports: emotional/informational has a small effect size (eta square), tangible, and affectionate large effects. PWE in paid work report significantly more PSI (small effect Cohen’s d). People who are well off report significantly more support than poorer people (tangible–medium effect (eta square), affectionate and PSI had both medium/large effect).

### The Effects of Support on Quality of Life

Adjusted R<sup>2</sup> showed that more than 45% of variability in QoL scores was shown in the model (see ►Table 4). In the block recursive regression, there were four determinants of QoL. Being in paid employment (*b*: −5.936) significantly increased QoL by nearly 6%. Each addition of \$250 of weekly household income (*b*: 1.560) increased QoL by one and one-half percent. Difference in seizures in the past 12 months (*b*: −6.965) meant that those having “one or more seizures per week” compared to no seizures reduced QoL by more than 20%. Finally, the only social support subscale (scored 0–100) to have a significant impact on QoL was positive social interaction (PSI) (*b*: 0.282). A 50% increase in PSI led to about 14% increase in QoL.

**Table 3** Sociodemographics by types of support

Support	Emotional/ n (%)	Mean (SD) <sup>a</sup>	95% CI		d/ $\eta^2$	Tangible n (%)	Mean (SD)	95% CI		d/ $\eta^2$
Gender										
Female	158 (71.8)	57.57 (30.02)	[52.85, 62.28]		d	164 (71.0)	68.00 (32.81)	[62.74, 72.86]		d
Male	62 (28.2)	64.82 (27.36)	[57.87, 71.77]	ns	0.25 S	67 (29.0)	71.64 (35.09)	[63.08, 80.20]	ns	0.12 S
Age										
18–34	50 (22.7)	70.22 (23.13)	[63.63, 76.79]			52 (22.5)	81.61 (26.38)	[74.27, 88.96]		
35–44	39 (17.8)	57.09 (31.59)	[47.85, 68.33]			41 (17.7)	66.16 (33.60)	[55.55, 76.76]		
45–64	96 (43.6)	56.72 (29.62)	[50.72, 62.72]		$\eta^2$	100 (43.3)	65.75 (33.24)	[59.15, 72.35]		$\eta^2$
65+	35 (15.9)	54.06 (31.81)	[43.13, 64.99]	F 3.01 p.031	0.04 S/M	38 (16.5)	62.83 (38.99)	[50.01, 75.64]	F 3.40 p.018	0.043 S/M
Education										
≤ year 12	64 (29.5)	64.75 (27.86)	[57.79, 71.71]			69 (30.6)	76.36 (31.81)	[68.71, 84.00]		
TAFE/trade	37 (17.0)	60.05 (28.61)	[50.51, 69.59]		$\eta^2$	35 (15.6)	66.07 (29.91)	[55.80, 76.35]		$\eta^2$
Tertiary	116 (53.5)	56.38 (30.25)	[50.82, 61.95]	ns	0.012 S	121 (53.8)	64.62 (34.07)	[58.37, 70.86]	ns	0.03 S
Living with										
Alone	37 (17.8)	54.27 (32.59)	[43.40, 65.13]			38 (17.7)	34.54 (34.16)	[23.31, 45.77]		
Partner/child	122 (58.7)	57.90 (29.50)	[52.61, 63.19]			125 (58.1)	72.60 (29.92)	[67.34, 77.86]		
Other family	40 (19.2)	72.77 (22.60)	[65.55, 80.00]		$\eta^2$	43 (20.0)	87.21 (21.39)	[80.83, 93.79]		$\eta^2$
Friends/Share	9 (4.3)	52.95 (27.70)	[31.66, 74.25]	F 3.50 p.016	.049 S	9 (4.2)	51.39 (28.60)	[29.40, 73.38]	F 25.04 p.000	0.26 L
In work										
No	109 (50.0)	58.32 (28.26)	[53.95, 64.68]		d	119 (52.0)	65.18 (36.08)	[58.63, 71.73]		d
Yes	109 (50.0)	60.16 (30.59)	[54.36, 65.97]	ns	0.03 S	110 (48.0)	72.39 (30.12)	[66.70, 78.08]	ns	0.22 S
Income										
\$0–749	58 (29.3)	54.15 (31.23)	[45.94, 62.36]			59 (29.1)	57.94 (36.66)	[48.39, 67.50]		
\$750–1749	85 (42.9)	59.39 (29.10)	[53.12, 65.67]		$\eta^2$	82 (40.4)	67.07 (32.11)	[60.02, 74.13]		$\eta^2$
\$1750+	55 (27.8)	63.64 (28.07)	[56.05, 71.22]	ns	0.02 S	62 (30.5)	82.34 (26.38)	[75.66, 89.06]	F 9.11 p.000	0.083 M

**Table 3** (Continued)

Support	Affectionate n (%)	Mean (SD) <sup>a</sup>	95% CI		d/ $\eta^2$	PSI n (%)	Mean (SD)	95% CI		d/ $\eta^2$
Gender										
Female	166 (71.6%)	74.48 (32.15)	[69.52, 79.38]		d	165 (70.6%)	60.71 (27.80)	[56.43, 64.98]		d
Male	66 (28.4%)	73.11 (31.28)	[65.42, 80.79]	ns	0.03 S	69 (29.4%)	61.72 (27.35)	[56.14, 68.29]	ns	0.04 S/M
Age										
18–34	52 (22.4)	81.41 (26.64)	[73.99, 88.83]			53 (22.7)	66.20 (28.73)	[58.82, 73.56]		
35–44	40 (17.2)	75.42 (30.07)	[65.80, 85.03]			41 (17.5)	65.45 (27.29)	[56.83, 74.06]		
45–64	106 (45.7)	69.97 (34.55)	[63.31, 76.62]		$\eta^2$	106 (45.3)	56.37 (27.90)	[50.99, 61.74]		$\eta^2$
65+	34 (14.7)	74.02 (31.50)	[63.03, 85.01]	ns	0.02 S	34 (14.5)	62.01 (27.32)	[52.51, 71.51]	ns	0.03 S
Education										
≤ year 12	68 (30.0)	72.67 (35.73)	[64.02, 81.32]			69 (30.3)	60.51 (29.80)	[53.35, 67.66]		
TAFE/trade	37 (16.3)	78.38 (27.81)	[69.11, 87.65]		$\eta^2$	37 (16.2)	59.01 (27.80)	[49.74, 68.28]		$\eta^2$
Tertiary	122 (53.7)	73.57 (30.54)	[68.09, 79.04]	ns	0.004 S	122 (53.5)	61.68 (26.78)	[56.88, 66.48]	ns	0.001 S
Living with										
Alone	39 (18.1)	47.65 (37.17)	[35.60, 59.70]			40 (18.2)	53.99 (29.72)	[44.45, 63.46]		
Partner/child	125 (57.9)	83.00 (24.21)	[78.71, 87.29]			127 (57.7)	63.19 (27.96)	[58.28, 68.10]		
Other family	43 (19.9)	80.81 (28.44)	[72.06, 89.57]		$\eta^2$	44 (20.0)	66.67 (25.23)	[59.0, 74.34]		$\eta^2$
Friends/share	9 (4.1)	47.22 (26.02)	[27.22, 67.22]	F 19.56 p.000	.22 L	9 (4.1)	54.63 (25.72)	[34.86, 74.40]	ns	0.03S
In work										
No	116 (50.4)	71.41 (35.07)	[64.96, 77.86]		d	117 (50.4)	56.77 (28.36)	[51.57, 61.96]		d
Yes	114 (49.6)	77.19 (27.38)	[72.11, 82.27]	ns	0.18 S	115 (49.6)	65.58 (26.39)	[60.71, 70.45]	t 2.45 p .015	0.32 S
Income										
\$0–749	57 (27.7)	59.36 (35.81)	[49.85, 68.86]			59 (28.4)	46.05 (28.38)	[38.65, 53.44]		
\$750–1749	87 (42.2)	77.68 (29.82)	[71.33, 84.04]		$\eta^2$	86 (41.3)	64.83 (25.90)	[59.27, 70.38]		$\eta^2$
\$1750+	62 (30.1)	83.74 (22.50)	[78.02, 89.45]	F 10.90 p .000	0.10 M/L	63 (30.3)	69.71 (23.82)	[63.71, 75.71]	F 14.19 p .000	0.12 M/L

Abbreviations: CI, confidence interval; L, large effects sizes; M, medium; ns, not significant; PSI, Positive Social Interaction; S, small; SD, standard deviation; TAFE, Technical and Further Education.

Note: Income weekly household income before tax. d Cohen's d  $\eta^2$  Eta squared.<sup>a</sup>p<.05.



**Table 4** Determinants of quality of life

Independent variables	b unstandardized coefficient	p-Value	95% CI
Age	−0.215	0.051	[−0.001, 0.431]
Gender (female)	−6.057	0.097	[−13.224, 1.110]
Education	1.868	0.342	[−2.002, 5.738]
Paid employment	−5.936	0.035	[−13.605, −0.502]
Income	1.560	0.032	[0.140, 2.979]
Seizures	−6.965	0.000	[−9.597, −4.332]
Drugs	0.932	0.421	[−1.353, 3.217]
Emotional support	0.044	0.414	[−0.062, 0.151]
Tangible support	−0.024	0.628	[−0.123, 0.074]
Affectionate support	−0.042	0.432	[−0.148, 0.064]
Positive social interaction	0.282	0.000	[0.166, 0.397]

Abbreviations: CI, confidence interval; QoL, quality of life.

Note: Adjusted  $R^2$  .455.

QoL scored 0–100.

Social support subscales scored 0–100.

### Qualitative Results

The MOS-SSS met our purpose of providing more nuanced detail of people's experiences in seeking support

► **Table 5** shows that most responses were related to emotional/informational needs with the greater number

reporting positive experiences, especially with assistance on information from epilepsy associations and professional counsellors. Also emerging in the responses were levels of emotional support on receiving information and knowing that the assistance could be depended on in future.

**Table 5** Qualitative responses

Support	Response numbers	Examples of responses
Emot/inf positive	68	<p>"If it makes me feel low, talking to them can help, put positive thoughts back. It can make me realize that life is manageable with this illness."</p> <p>"Epilepsy organisation support - they train carers/family members in Midazolam administering for our son. They helped us organise accommodation for our family whilst our son had multiple surgeries for epilepsy. They helped educate us on epilepsy."</p> <p>"I like my Neurologist - empathetic, light-hearted, kind and understanding. She understands it's a big deal but doesn't make it a big deal. Thorough, knowledgeable and experienced. She gets me."</p>
Emot/inf negative	16	<p>"Got no help from local epilepsy association."</p> <p>"I had one psychologist laugh at me....which obviously did nothing for my confidence."</p>
Tangible positive	4	<p>"The NDIS (National Disability Insurance Scheme) is available now. I have registered and have recently had my plan approved s. It includes some assistance with transport, psychological support and practical help at home."</p>
Tangible negative	11	<p>What I find EXTREMELY difficult is accessing the money to pay for the essential support services. I'm drowning financially to keep my head above water</p>
Affectionate	1	<p>A person who gives "loving emotional support and who listens, takes the weight of fatigue and worry off your shoulders."</p>
Affectionate negative	2	<p>"Realised partner did not care about me."</p>
Social int. positive	14	<p>"Epilepsy support groups are an excellent way to feel disinhibited about discussing the day-to-day issues and emotions of living with epilepsy."</p> <p>"Fun, I am going on short-term accommodation and have fun, go to cooking and activities."</p> <p>"Being in positive surroundings and focussing on the positive is the best cure for me."</p>
Social int. negative	4	<p>"I am a loner. I accept that a lot of older ladies live alone."</p> <p>"My anxiety is extremely severe and so is my depression because of the scars, teeth, bruising, migraine etc honestly I feel completely alone."</p>

Comments such as “made me feel I was not alone” appeared several times. One respondent related that support from an epilepsy association led to being able to drive again and meant she was independent of an abusive husband. Negative emotional/informational experiences were also informative. These largely related to not receiving information specific to that person's needs, finding that services were not available where the person lived, or not being able to access professional services due to cost or being unable to travel. However, some reported failure to have their needs taken seriously by health professionals or epilepsy associations, which possibly resulted in poorer emotional outcomes for that person.

Reports of social interaction fell into both positive and negative experiences. In social interaction, acceptance as a person with epilepsy is the primary concern. Peer support plays a role here, both in groups, and one-on-one, as does employment and the social benefits it confers. In nearly all cases of negative social interaction, isolation was self-imposed to avoid stigma.

Tangible support largely concerns access to services to assist daily living such as carers to undertake shopping, housework, and transport. Inability to drive was a strong feature of negative tangible support as was not being able to afford some assistive services.

## Discussion

One of the outcomes of the quantitative analysis was that being older, being poor, and living alone equated with less support. In particular for emotional/informational and tangible, being older equated with significantly less support. Being poorer meant having less of each type of support.

In terms of the effects of sociodemographics on each of the four types of supports under the MOS-SSS younger people 18 to 34 years compared to 65+ years had more emotional/informational (mean: 70.22, 54.06) and tangible support (81.61, 62.83), as do people who live with other family compared to those with partners and/or children or live on their own. For emotional/informational support living with other family members (mean 72.77) compared to living alone 54.27, for tangible support 87.21 compared to 34.54, as well as affectionate support (80.81 compared to 47.65). While this result was unexpected, it has been reported in other contexts.<sup>21,22</sup> Walen and Lachman<sup>21</sup> used a large sample of 2,348 adults aged between 25 and 75, to investigate associations of social support and strain with well-being and health and whether these association depended on the types of relationships. They found that both positive and negative social support were more related to well-being than health and that friendships were buffering in instances of partner strain but only for women. Older adults reported more family and friend support and less strain than younger and middle-aged adults. They found the following support variables differed for males and females. Family was higher for females (3.51) compared to males (3.44). Friends were higher for females (3.31) than for males (3.10), whereas partner was lower for females (3.46) than males (3.67).

Those in paid work report more PSI and those well-off report more tangible and affectionate support as well as more PSI. Being well off, as well as being in paid work provided more opportunities for interacting due to having more resources: this also affected some other types of support, such as seeking tangible support through professional help.

This study reported that of the different dimensions of social support it was only PSI that was a significant predictor of QoL. It had a strong impact, Cano-López et al<sup>23</sup> also found social support (and again only positive social interaction) to be a significant predictor of QoL. Using regression analysis, they found PSI had a significant effect ( $p=0.008$ ) with an unstandardized ( $b$ ) score of 0.32. Contrary to the findings of this reported study, they did not find that frequency of seizures was a QoL predictor. They also found anxiety, depression, neurosensory symptoms, and long-term verbal memory significant predictors: however, these were not included in the study reported here. This study found that being in paid employment and increased household income also predicted positive QoL.

Whatley et al<sup>9</sup> report a significant positive association between social support and QoL for PWE. However, they measured social support by the second part of the personal resource questionnaire. It is a 25-item scale and items are individually scored with a 7-point Likert scale. They argue supportive relationships create an environment of encouragement, sharing positive life events, and cushioning negative situations. They found through regression analysis that regimen specific support significantly predicted QoL (beta standardized  $-0.240$ )  $p < 0.001$ . Among PWE, support can also include helping people with their treatment regimens, such as reminding one to take his or her medications.

Charyton et al<sup>16</sup> in the California Health Interview Survey analyzed four support questions from the MOS-SSS. For emotional/informational support, 210 PWE recorded poor support and 340 reported good support. For tangible support, 277 recorded poor and 273 reported good support. For affectionate support, 162 PWE recorded poor support and 388 good. Finally, for PSI, 278 PWE recorded poor support and 272 good support. Having poor affectionate support as well as epilepsy affected self-rated health status compared with reporting only one or the other. Lacking affectionate support adversely affects health status more for those with epilepsy compared to those without. For those with epilepsy having poor social support were most likely to report poor self-rated health. Self-rated health, however, was not included in the reported study.

The qualitative analysis of responses contributes to deeper understanding of support in the lives of PWE. We have analyzed the responses to the question of how support from a range of sources helped them. In our analysis, we broadened the concept to include positive and negative support<sup>14</sup> and applied the MOS-SSS terminology in which to examine the responses. While Unalan et al<sup>10</sup> found that the religious context was important for some Turkish PWE, in Australia the context relates to access issues associated with the Australian health system. As a universal health care



system, it is largely medical and surgical care that is covered. For those unable to afford private health insurance, professional psychological support may need to be paid for and is not always available in regional Australia. Lack of access constitutes negative emotional/informational support:

“Counselling/psychological support is helpful to a point, but hard to access when working full time and no driver’s license”

Additionally, inability to form a relationship with a psychologist or finding the psychologist knew little about epilepsy constituted negative support.

“Mental health counselling was useless in understanding epilepsy but relationship ok.”

However, many found such emotional/informational support from professionals positive:

“They help me gather my bearings and expose the holes in my own warped logic”

“A few counselling sessions helped recently with work and life stresses, enabled me to make positive changes to restore work life balance”

Emotional/informational support from epilepsy associations was also largely positive due to the tailored advice specific to the person’s diagnosis and coping abilities. Being accessible by phone and free also constitutes positive support. A small number regretted not getting tailored help or the closure of regional centers.

PSI was highly valued and most notably as peer support, either one-on-one or as group support. Epilepsy association functions such as camps or being given contact with another person with epilepsy were examples of this. This supports the quantitative findings around QoL. Interestingly examples of negative social interaction were related to fear of being exposed to stigma, either by being identified as a PWE or because of physical appearance. It was clear that isolation to avoid such exposure was a decision the person had made deliberately.

Tangible support, while valued by those who had access to services, was not always available or affordable by those who could benefit from it. This reflects again the Australian funding system, PWE not disabled enough to qualify for the National Disability Insurance Service have few other sources of help. Consequently, there were more negative responses reflecting its absence.

Affectionate support received little attention in the responses, and this may be related to people’s wish for privacy. Unexpectedly there were two instances of negative responses: one where the onset of epilepsy revealed a partner’s lack of responsiveness and the other where emotional/informational assistance from an epilepsy associ-

ation gave the person independence from an abusive domestic partner.

## Conclusion

Using MOSS-SSS assisted in developing a broader and clearer picture of the services PWE sought and valued as well as those who fell short of meeting their needs or were not accessible.

The quantitative and qualitative responses demonstrate that employment provides access to a range of supports including social interaction, emotional/informational, and tangible services. Also notable was the importance of PSI is important to QoL. Engaging in work is one way for those who are able to do so. If that is not an option engaging with others in joint activities, such as peer support is valuable.

This study uses data collected before the coronavirus disease 2019 (COVID-19) pandemic. We acknowledge that since then certain needs for different types of support may have changed due to Australian COVID-19 lockdown measures and elements of the virus. Given the social exclusions brought about by COVID-19 lockdowns and the need to be more homebased, many people now rely on technological devices for their social activities. Of much interest will be data on PWE support gathered during COVID-19, and to see how they deal with the many social restrictions which have ensued.

## Conflict of Interest

None declared.

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