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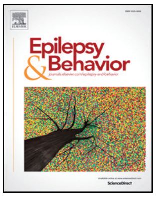

Needs for aids and equipment for the management of epilepsy in an Australian cohort

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ABSTRACT

Aim: This paper investigated the bases of needs for a range of epilepsy aids and equipment and expressed concerns about the use of such devices.
Method: There was a 29.6% response rate ($n = 393$ of 1328) to Wave 4 of the Australian Epilepsy Longitudinal Study (AELS). The focus of Wave 4 was on the expressed needs and affordability of aids and equipment for people with epilepsy (PWE) and quality of life (QoL). Quantitative analysis was used to examine the association between self-reported need for aids and equipment, sociodemographic information, and QoL. Open-ended responses were subject to qualitative analysis.
Results: Approximately one-fifth of the sample felt that they needed specific aids, including emergency ID bracelets, seizure alarms, and seizure monitors. Those respondents who felt that they needed aids had more frequent seizures, had been recently injured by a seizure, and were less prosperous. The QoL of those in need of equipment was lower than that of those who felt that they did not need it. Qualitative analysis revealed a need for more information about the aids available, issues associated with affordability, and some concern about the utility of these aids for those who lived alone.
Discussion: Much research to date has focussed on the development and validation of devices for PWE and standards for testing. Fewer studies deal with the needs and experiences of PWE with regard to the use of such equipment. The development of these devices needs to ensure patient comfort and acceptability. In addition, there is a need to canvas the views of family, caregivers, and primary care providers on the usability of epilepsy aids and equipment.
Conclusion: Further person-centered research is needed in assessing the need for and usability of aids and equipment for the management of epilepsy.

1. Introduction

Epilepsy is a neurological condition characterized by recurrent and unpredictable seizures, which the World Health Organization reports affects approximately 50 million people worldwide [1]. Unpredictability in epilepsy remains one of the most distressing factors for people with epilepsy (PWE) in the community because of the associated anxiety, as well as increased risk of injury and other vulnerabilities [2]. In order to assist in the management of risks associated with seizures, a number of different aids and equipment have been brought onto the market over the years [3]. We define aids and equipment as those items and assistive technologies designed to improve the ability to predict seizures and increase safety in epilepsy in the event of a seizure. These include seizure alert devices, antisuffocation pillows, and seizure dogs.

Over recent years, there has been a steady increase in the development and examination of the efficacy and quality of devices. A recent systemic review of the evidence for seizure detection devices pointed towards a paucity of studies in this area [4]. No single device could accurately predict all seizures, and there are ongoing difficulties predicting and/or detecting focal seizures. Wearable devices were typically rated highly for use by PWE and for seizure detection, whereas less common aids such as seizure dogs show mixed efficacy for seizure prediction [4]. As such, current research indicates that the effectiveness and usability of seizure detection devices are still in the relatively early stages. Beyond

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devices for seizure detection, useful aids and equipment for the management of epilepsy include antisuffocation pillows, intended to reduce the risk of SUDEP or suffocation following a nocturnal seizure, as well as home alterations such as double-hinged doors to increase ease-of-access for support persons in the event of a seizure.

Despite a recent surge in interest in seizure detection and the development of useful devices, there has been little systematic examination of the views of PWE with regard to the aids and equipment available to them [2]. Focussing on the human side of technological advances has been argued to be a key requirement of the process of testing and evaluating new devices, with acceptance and comfort of devices by PWE critical to their successful uptake [5]. Understanding if, how, and why PWE use aids and equipment for the management of their epilepsy can direct research towards the development of tools that are more likely to have real-world benefits.

Schulz-Bonhage et al. [6] consulted patients with uncontrolled epilepsy in Germany and Portugal and concluded that the devices available on the market at that time would need to improve in their predictive effectiveness to meet safety and wearability expectations of users. A more recent study examining patient, caregiver, and healthcare professionals' views of remote health management technology (including internet and smartphone apps and seizure detection devices) identified a number of common experiences [6]. Namely, over half of the PWE did not own any wearable devices, but many (>60%) were interested in them. This interest was not dependent on age, gender, seizure type, or frequency. People with epilepsy were interested in the benefits of increased knowledge of their epilepsy for self-management, as well as for sharing with healthcare professionals and for altering relatives in the event of an emergency [7].

This early research into understanding the perspectives of PWE on the devices, aids, and equipment available to them is a critical part of the process of technology development. The current study seeks to further extend upon this work by gaining an understanding of the mix of factors involved in PWE's need for aids and equipment, including affordability, and quality of life (QoL) in relation to self-reported ability to access important aids and equipment. This aim was investigated via a mixed methodology, utilizing both quantitative and qualitative data in order to gain an understanding of the perspectives of PWE with regard to their knowledge of relevant aids and circumstances affecting their use.

2. Method

2.1. Participants

As part of the Australian Epilepsy Longitudinal Survey (AELS), participants are sent survey 'Waves' approximately every three years, with previous waves conducted in 2006, 2010, and 2013. In 2016/17, 393 or 29.6% self-selecting participants from the Australian Epilepsy Research Register (AERR) completed the Wave 4 survey. This included 355 (91.3%) who identified as a person with epilepsy >18 years and 34 (8.7%) who identified as the parent or caregiver of someone with epilepsy <18 years. Given the focus on QoL as measured by a self-report instrument and because of the small numbers, information relating to those under the age of 18 years was excluded from the current study. The majority (70.2%) were identified as living in urban areas and were also predominantly from Victoria, Australia (61.8%).

Participation is voluntary, and all participants provided informed consent in line with the Declaration of Helsinki. Ethics approval was gained from Deakin University Human Ethics (2013 – 011).

2.2. Wave 4 survey

A questionnaire was distributed to participants of the AERR, either in hardcopy or online (Survey Monkey) in 2016/17. For each Wave of the AELS, information is obtained on sociodemographic, epilepsy diagnosis, seizure information and treatment, QoL, as well as participants' perspectives on living with epilepsy. For the purposes of the current study, self-reported prosperity was judged according to participant response regarding whether they feel they are "prosperous", "very comfortable", "reasonably comfortable", "just getting along", "poor", or "very poor". A particular focus for Wave 4 was on collecting information on the experiences of utilizing services and equipment for the treatment and management of epilepsy. Previous publications from Wave 4 have detailed participant experiences of emergency department and need for services at first diagnosis [8].

The survey instrument had the following sections:

Sociodemographic information (12 questions), living with epilepsy (23 questions), QoL (31 questions), access to treatment and medical care (7 questions), and needs and services for epilepsy (15 questions). The current study set out to examine participant experiences with the aids and equipment listed in Table 1. This included forced choice questions about whether participants (i) needed but did not have the relevant equipment, (ii) needed but could not afford the equipment, as well as (iii) reasons for the difficulty in accessing aids and equipment. Open-ended questions also allowed participants to elaborate on the equipment they needed. Twenty-one participants responded to the open-ended questions, and these data were used for the qualitative analysis. Further information on the survey questions can be found in Supplementary Fig. 2.

2.2.1. Quality of life

The Quality of Life in Epilepsy-31 items (QOLIE-31), a well-established measure of QoL specifically in PWE, was also included in Wave 4. The QOLIE-31, an abbreviated version of the QOLIE-89, includes subscales focussing on the impact of epilepsy on important areas of physical (effects of medication, energy/fatigue, and cognitive functioning), social (work, driving, and social restrictions), and psychological/emotional functioning (seizure worry, overall QoL, and emotional well-being). Higher scores reflect better QoL. The overall QOLIE-31 and subgood internal consistency and test–retest reliability [9].

2.3. Data analysis

Quantitative analyses were undertaken with the statistical package SPSS version 24 (IBM Corp. 2016, NY). For categorical and ordinal data (presented in Table 2), correlational analysis is undertaken using Cramer's V and Gamma. Where continuous data such as QoL are used

Table 1
Information on the aids/devices included in the survey.

Aid/device	Information
Emergency ID bracelet	A tag outlining the epilepsy condition on a medical bracelet which can help in the case of an emergency. Various prices starting from AUD$8.
Seizure alarm	There are a number of devices to provide a seizure alarm. Some of these may be worn or attached to a bed. Prices may be up to AUD$880 There are a number of apps available also, mostly free of charge.
Seizure monitor	A device that detects seizures. These can include a bed sensor, a video-based movement detection system, a wearable device detecting falls, a smart watch, and others. Starting purchase price from approx. AUD$400.
Antisuffocation pillow	Pillows manufactured to help an individual stay in a safe and secure sleeping position, with layering in the pillow designed to ensure breathability. Cost from AUD$145
Emergency door hinges	These are double hinges for doors so that they can be opened either way in case something is blocking the doorway.
Other (e.g., lifting aids)	A range of devices that may help to increase safety around the home.

Note. This information is provided for publication only. Participants were provided with the name of the aid/equipment only.

Table 2
Contributing factors to need for equipment among adults living with epilepsy.

Equipment	Contributing factors	Correlation Coefficient	p
ID bracelet	No clear medical communication	0.204^{g}	.035
n = 86			
Seizure alarm	Not employed	0.134^{cv}	.013
n = 41	Living alone	0.212^{cv}	.000
	More frequent seizures	0.308^{g}	.009
	Greater time since diagnosis	0.325^{g}	.015
	Been injured[a]	0.169cv	.009
	More AEDs	0.383^{cv}	.029
	Less prosperous	0.339^{g}	.006
Seizure monitor	More frequent seizures	0.506^{g}	.000
n = 36	Been injured[a]	0.175^{cv}	.006
	More AEDs	0.325^{g}	.013
	No clear medical communication	-0.323^{g}	.013
	Less prosperous	0.369^{g}	.007
Antisuffocation pillows	Living alone	0.115^{cv}	.032
n = 34	More frequent seizures	0.417^{g}	.001
	Been injured[a]	0.159^{cv}	.003
	Less prosperous	0.277^{g}	.038
Emergency door hinges	Not employed	0.182^{cv}	.000
n = 15	Been injured[a]	0.182^{cv}	.001
	Less prosperous	0.458^{g}	.029
Other (e.g., lifting aids)	Male	0.171^{cv}	.006
n = 18	Not employed	0.130^{cv}	.016
	More frequent seizures	0.409^{g}	.030
	Been injured[a]	0.206^{cv}	.001
	Less prosperous	0.464^{g}	.015

^{g} Gamma, ^{cv} Cramer's V.

[a] Been injured because of a seizure in the last 12 months.

(see Table 3), *t*-tests are used. In both cases, significance <.05 is used. Effect sizes (Cohen's d) have also been presented. Missing data were excluded listwise from each analysis, with further details of missing (n) reported in Table 3.

For the qualitative analysis, open-ended responses of 33 respondents were analyzed using a thematic approach. An explicit thematic approach was chosen which aimed to classify data into meaningful and relevant categories based on the assumption that an understanding of participant experiences can be 'explicitly' identified in their responses [10,11]. Data were first coded inductively line-by-line by HC. Common themes were then sought within and between codes. Thematic saturation is considered to have occurred when examination of the responses does not reveal any further themes. Consensus on final themes was then reached through discussion among the researchers (CP, HC, & CW).

3. Results

3.1. Participant demographics

Mean age at the time of survey was 45.15 years (standard deviation [SD] = 14.61, n = 355 [range: 18–83]), with 67.5% female. Briefly, 34.0% had a university degree or higher; 50.0% were in paid employment; 18.8% lived alone; 36.4% had been diagnosed as having epilepsy in the last 16 years; 15.1% had seizures at least once per week; 41.8% were taking ≤one antiepileptic drug (AED); and 44.3% considered themselves to be at the lower end of the income range ('very poor' to 'just getting along').

3.2. Supports needed to manage the epilepsy

The most common device that participants felt would be helpful to manage their epilepsy was an emergency ID bracelet (24.2%), followed by seizure alarm (11.6%), seizure monitor (10.1%), and antisuffocation pillow (9.6%) (Fig. 1).

3.3. Factors associated with a desire for aids and equipment

Factors associated with reported need for the different devices were then explored using Gamma and Cramer's V correlations (Table 2). Overall, a reported need for seizure monitoring devices was more likely to be reported by those participants with more severe epilepsy and a lower self-reported prosperity. Specifically, reported need for aids and equipment was reported more commonly among those who were less well off, less likely to be in paid employment, having more frequent seizures, and those more likely to have been injured during a seizure.

Among those participants living alone (n = 65, 18.8% of the adult sample), there was a relatively higher proportion reporting need for aids or equipment. This included 17 (41.5%) of those needing a seizure alarm, nine (25.0%) who needed a seizure monitor, six (33.3%) needing other equipment such as lifting aids, and six (40.0%) of those needing emergency door hinges.

3.4. Those in need of aids and equipment reported lower QoL

The total QOLIE-31 score for the sample was 55.98 (SD = 19.78, n = 3420 [range: 6.34–96.20]. Table 3 outlines the QoL for those who felt that they needed aids and equipment versus those who did not. In line with the epilepsy burden associated with needing equipment (described above), this group also reported lower QoL.

Table 3
Quality of life [M(SD)] of those adults in need of equipment compared with those who felt that it was not needed.

Equipment		n (%)	Mean (S/D)	t	p	Difference *Cohen's d*
ID bracelet	Need	85 (26.6%)	50.39(18.71)	3.07	.002	7.61
	Do not need	235 (73.4%)	58.00(19.81)			*0.40 small*
	Missing 34					
Seizure alarm	Need	41 (12.8%)	47.22 (18.57)	3.07	.002	10.04
	Do not need	279 (87.2%)	57.27 (19.75)			*0.53 medium*
	Missing 35					
Seizure monitor	Need	36 (11.3%)	41.71 (16.42)	4.75	.000	16.08
	Do not need	284 (88.7%)	57.79 (19.53)			*0.90 large*
	Missing 35					
Antisuffocation pillow	Need	34 (10.6%)	43.56 (15.36)	3.96	.000	13.98
	Do not need	286 (89.4%)	57.45 (19.76)			*0.79 large*
	Missing 35					
Emergency door hinges	Need	15 (4.7%)	47.30 (23.22)	1.75	ns	9.10
	Do not need	325 (95.3%)	56.41 (19.55)			*0.43 small*
	Missing 35					
Other (e.g., lifting aids)	Need	18 (5.6%)	39.30 (16.35)	3.77	.000	17.67
	Do not need	302 (94.4%)	56.97 (19.55)			*0.98 large*
	Missing 35					

Note. M = mean; Need = those PWE who reported a subjective need for the equipment (versus those who did not); SD = standard deviation.

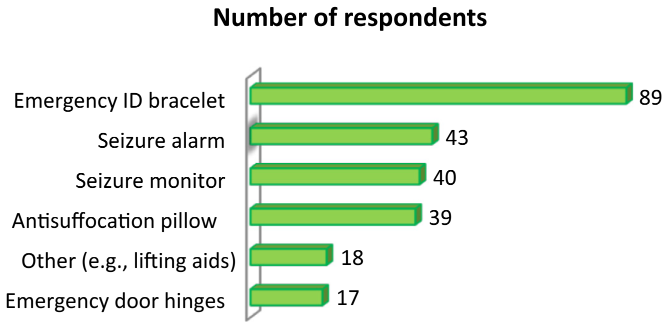

Fig. 1. Aids and devices patients feel they needed.

The largest differences in QoL were seen with regard to needing ‘other’ equipment (such as lifting aids), seizure monitors, and antisuffocation pillows (Table 3).

3.5. The importance of ability to afford aids and equipment

Given the increased reported need for equipment among those with lower self-reported prosperity (Table 2), we also sought to examine the impact of ability to afford equipment on QoL. For each device, those who reported need were separated according to self-reported ability to afford said devices. More than half of the respondents who needed certain equipment reported that they could not afford them. Typically, those who could not afford the aids and devices reported lower QoL (Table 4). It must be noted, however, that the numbers in this analysis are small.

3.6. Qualitative responses

The qualitative responses of participants revealed that the two main reasons preventing use of equipment were a lack of knowledge about the equipment available and/or the cost.

> “*I have never heard of a seizure alarm or seizure monitor*”

> “*Have never heard of these door hinges.*”

> “*I struggle to pay rent and bills, groceries and bring up a child let alone trying to buy something for myself.*”

> “*I wear a medical bracelet from the chemist as it's the cheapest one.*”

Those reporting why they used equipment typically referred to a need for reassurance.

> “*Anything to ease my fear.*”

This was often the case for those living alone; however, PWE living alone often felt that the devices and equipment available was not useful or relevant for them because the outcome often involved alerting other people.

> “*The whole thing is, I live alone. So there's very little I can do with many items (As they are warning devices for others like alarms etc. etc.) Not much bloody good, when I'm out of it doing as I do really, eh?*”

> “*I cannot find anything for anyone living alone????*”

Some participants noted specific aids or equipment that they would have preferred, including seizure companion dogs, special glasses for photosensitive epilepsy, and home modifications.

One participant reported that the use of an ID bracelet was not useful because “*no one read it.*”

4. Discussion

The current study presents findings of an Australian community sample of PWE with regard to their experiences and needs for a range of equipment and aids. Overall, approximately one-fifth of our sample reported a subjective need for equipment to help manage risks associated with their seizures. They tended to be those PWE with more severe epilepsy as well as those with less social and financial support available – i.e., those PWE more likely to be living alone and reporting a lower level of prosperity. Those who reported a need for aids and equipment also reported lower QoL although this was no doubt also influenced by the socioeconomic profile of this group. It should also be noted that self-report of need for equipment is likely to result in an underestimation of those who may benefit from aids and equipment for epilepsy because of the self-reported lack of knowledge within the community of the types of aids available.

On further examination of need for specific types of aids and equipment, there was a clear relationship between epilepsy-related factors and type of equipment needed. For example, those PWE wanting seizure alarms, seizure monitors, antisuffocation pillows, and equipment such as lifting aids had more frequent seizures that in most cases were more likely to result in injury and reported a lower income. Those PWE reporting a need for emergency door hinges (which open both ways to allow ease of access for others if the door is obstructed) were more likely to have been injured in a seizure and to be unemployed. Finally, those requiring an ID bracelet reported poorer communication from their medical provider. Given ID bracelets are relatively inexpensive and serve a primary function of communicating one's diagnosis, some PWE may feel an increased sense of security having a tool to clearly communicate their diagnosis. In this way, PWE may also be drawing on the use of aids and equipment to compensate for perceived gaps in the healthcare system. This suggests a greater need for communication between healthcare professionals and PWE around how and

Table 4
Comparison of QoL for adults based on ability to afford equipment.

Equipment	n (%)	Mean QoL (SD) of those who cannot afford equipment		Difference in QoL compared with those who can afford equipment	
ID bracelet	20 (23.5%)	41.53 (15.27)	34.38, 48.67	−11.59	p: .014
Seizure alarm	22 (53.7%)	44.05 (15.16)	37.32, 50.77	−6.85	ns
Seizure monitor	24 (66.7%)	41.21 (16.12)	34.41, 48.02	−1.49	ns
Antisuffocation pillow	14 (41.2%)	45.73 (14.00)	37.64, 53.80	+3.68	ns
Emergency door hinges	7 (46.7%)	49.24 (32.82)	18.88, 79.60	+3.63	ns
Other (e.g., lifting aids)	11 (63.6%)	37.62 (16.75)	26.37, 48.88	−4.31	ns
		41.93 (16.62)			
	7 (41.9%)				

Note. QoL = quality of life; SD = standard deviation.

why aids and equipment are used, as well as a need for greater understanding as to how others around the PWE, including healthcare providers and first responders, use these devices.

Self-reported prosperity emerged as an important factor related to perceived need across all types of aids and equipment. In explaining that a proportion of PWE could not afford particular aids or equipment, the characteristics of the self-selecting community sample are important to consider. Employment and self-reported financial difficulties characterized a small but significant proportion of the sample surveyed despite a reasonable proportion of people with a university level education. Less than half of respondents were in paid employment. This contributes to the financial strain associated with living with epilepsy and therefore ability to access aids and equipment for epilepsy management. The impact of socioeconomic status on ability to access important aids and equipment has also been reported in other neurological conditions. A self-report study of the use of assistive technologies for multiple sclerosis found that those participants who were older and less educated with a greater level of disability were the least likely to have aids [12]. The importance of considering socioeconomic status can also be clearly seen when noting that for multiple sclerosis (in Australia in 2017), personal costs for accessing aids and equipment were between $2729 and $16,995 per year [13].). To date, there is far less known about access to aids and equipment and their availability and affordability for PWE.

Currently, much of the literature on aids and equipment for the management of epilepsy focusses on seizure detection, including choices about which devices best suit the seizure profiles of PWE [14] and whether devices may be able to predict seizures [15,16]. Typically, seizure detection devices are designed to detect motor movement, which only occurs in some seizure types. While they are seen as important to keeping partners, family, and other carers involved in the management and control of seizures [7], as noted by our participants, the ability to detect a seizure and alert a carer or family member may be less useful for those PWE living alone.

In a study of 141 PWE, more than 90% felt that developing seizure detection was important [17]. Previous studies examining patient perspectives of seizure detection devices point to the benefits of increased epilepsy-related knowledge for self-management, providing more security in an emergency, alleviating some of the concerns of caregivers and reducing the carer workload, and improving general care by providing clinicians with more information [7]. However, the current study found that a number of PWE did not know about different types of equipment and wanted better information about what was available. There was also a high need reported for aids and equipment other than seizure detection devices, including ID bracelets to communicate diagnostic information, as well as equipment to ensure the safety of PWE in the event of a seizure at home. This broader perspective of considering both prediction and seizure management is important to promote greater self-control and self-mastery through limiting the impact of severe epilepsy where possible. As noted by Bruno et al. [7], caregivers are also supported by the use of devices which may help to reduce caregiver anxiety and improve both caregiver and PWE QoL. Understanding the perspectives of family and caregivers with regard to the use of aids and equipment is therefore an important avenue for further research.

5. Strengths and limitations

A number of limitations with the current study must be acknowledged. While the overall sample was robust for quantitative analysis, the relatively smaller numbers providing open-ended responses resulted in a small sample size for the qualitative data. Furthermore, the study cohort was largely represented by those PWE living in Victoria. As such, their views may not be representative of the broader Australian community of PWE, particularly those living in more rural and remote areas.

It would also have been useful to gauge participant understanding of devices from the sample as they were not provided with specific definitions for each aid/piece of equipment. Participant understanding of the relevant devices was felt to be reflected in the qualitative data, which showed a relatively good understanding of what the equipment was but perhaps less clarity on the degree of usefulness of all of the aids/equipment.

It should also be noted that there were other variables important to QoL not included in the current analysis. Factors such as mood and social support are known to impact QoL and may moderate or mediate the impact of being able to afford aids and equipment. The focus of Wave 4 of the AELS was specifically on participants' use of services, aids, and equipment for the management of their epilepsy. Further questions about broader factors that may be influencing QoL were not included in order to keep the survey shorter to ensure tolerability of the overall survey and maintain rapport with the participants of the AELS. The current study was not, however, intended to characterize QoL in a community sample of PWE per se but rather to highlight factors associated with participant use of different aids and equipment for the management of their epilepsy.

Strengths of this research lie in the large number of participants recruited from a community sample, as well as the ability to examine QoL against self-reported access to aids and equipment across the whole sample. The mixed methods approach also provided a richer view of the respondents' needs and their distress at a lack of access to those aids and equipment they felt would assist them.

6. Conclusion

In conclusion, the current study points towards a relationship between more severe epilepsy, lower financial and social resources, and greater perceived need for aids and equipment among PWE. Those reporting a need for aids and equipment for the management of their epilepsy also reported lower QoL. Qualitative responses from participants pointed towards a lack of knowledge about the range of resources available. Current research in this field shows a general lack of information on whether PWE have access to digital services and technology for seizure detection [7] but a notable desire on the part of PWE for aids that are able to detect all seizure types [18]. While this technology may still be many years away, it is important to continue to include the perspectives of stakeholders throughout the process of research and development. Person-centered research focussing on the needs of PWE and their families, such as that presented in the current paper, is therefore critical.

Supplementary data to this article can be found online at https://doi.org/10.1016/j.yebeh.2020.107062.

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Ethical publication statement

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

Declaration of competing interest

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

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