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‘I hate wasting hospital’s time’: Experiences of emergency department admissions of Australian people with epilepsy

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Abstract

Aim

This paper investigates the reasons and extent of hospital emergency departments (ED) attendance by people with epilepsy in Wave 4 of The Australian Longitudinal Survey 2016-17.

Method

Wave 4 had 393 respondents who completed the survey, which included questions relating to their use of hospital and healthcare services. Of these, 121 (31%; 82 female) reported one or more admissions to the Emergency Department (ED) within the previous 12 months. We conducted a mixed methods analysis – using quantitative measures to explore the type and number of admissions, factors relating to increased admissions and a qualitative approach to explore respondent experiences of their admissions.

Results

Over half of the admissions reported were seizure-related, including injuries occurring as a result of seizures. More than 15% of respondents had more than four ED visits during the preceding 12 months of the survey. Those who had experienced seizures within the previous 12 months, irrespective of frequency, were more likely to have attended the ED compared to those who had not experienced a recent seizure. Self-reported income was another major factor in ED use.

Experiences of hospitalisation demonstrated frustration at being taken to the ED, loss of autonomy and experiences of inappropriate care due to poor understanding of

epilepsy. Some respondents did not want to waste the ED time as they felt rest was all they needed following a seizure.

Discussion

The rates of hospitalisation for seizure-related reasons are in line with findings of other epilepsy-related studies, as is the increased hospitalisation rate of those from less well-off backgrounds. This study provided a valuable picture of the opinions and attitudes of people with epilepsy towards their healthcare services.

Conclusion

While this is an analysis of a small cohort, the consistency of reported experiences suggests that ED is not always felt to be appropriate following a seizure, and misunderstanding around the appropriate treatment of epilepsy continues in healthcare services.

(Abstract 288 words)

Keywords

Hospitalisations Emergency department Mixed methods analysis Health care

1. Introduction

Epilepsy is a common neurological condition, characterised by recurrent unpredictable seizures. Estimates of the number of individuals living with epilepsy across the lifetime have varied between 1-4%, [1-3] which may be as many as 1 in 25 Australians. Despite these numbers, research investigating the impact of living with epilepsy has shown that there is limited understanding of epilepsy and its associated risk factors in the general population, as well as among health professionals [4, 5]. This has important implications for utilisation of healthcare services.

Two recent Australian studies found that epilepsy-related hospitalisations constitute a substantial cost to the healthcare system despite the fact that epilepsy/ seizures has been identified as one of the top ten avoidable causes of hospitalizations [6, 7]. Not only did hospitalisation costs for epilepsy and status epilepticus equate to approximately \$AU80.6 million per annum in New South Wales (not including indirect costs to patients and their families), but a South Australian survey found that seizure-related hospitalisations were higher than those for diabetes [1, 3]. Hospital admissions for epilepsy/ seizures are also typically longer than those for asthma or angina [7].

The link between poor seizure control and increased healthcare costs, as a result of both direct and indirect causes, is a consistent finding in the literature. Direct causes may include the seizure itself and/or status epilepticus, while indirect causes can include increased risk of injuries for patients with poorly controlled seizures [1, 8]. Unnecessary ED admissions for seizures or for seizure-related injuries represent preventable hospital admissions. To date, research has suggested that hospitalisations can be reduced by improving seizure control, through mechanisms such as use of newer anti-epileptic drugs (AEDs), improved quality of management in primary health, as well as better patient education, counselling and seizure-management support [9, 10]. However, in order to gain a better understanding of unnecessary hospital admissions, it is important to take a person-centred approach to include the perspective of people living with epilepsy on necessary versus unnecessary hospitalisations.

The aim of this study was to better understand the needs of people with epilepsy in health services and related support services. To this end, we investigated ED admissions among Australian people living with epilepsy, who participated in the Australian Longitudinal Survey of Services and Equipment for Epilepsy, 2016/17. In this article we present an analysis of a subgroup of respondents to this survey to explore a sample of individuals' experiences of ED admissions, including their concerns of the appropriateness of the presentations and their suggested alternatives.

2. Methods

The 2016/17 Australian Epilepsy Longitudinal Survey was distributed to participants on the Australian Epilepsy Research Register (AERR). The AERR is an Australian-wide register run by the Epilepsy Foundation that is open to adults 18 years of age or older who have epilepsy or a seizure disorder as well as parents/ guardians, or carers/ friends of a person with epilepsy/seizure disorder. Participation in the survey 'waves' is voluntary.

This study represents an initial analysis of Wave 4 of the Australian Epilepsy Longitudinal Survey, which also includes three previous surveys (2006, 2010 and 2013). Data from Waves 2 to 3 have been reported on elsewhere [5, 9, 11,12]. Wave 4 had 393 respondents from a sampling frame of 1,328, giving a response rate of 29.6%. Data was collected via regular mail-out or online survey (via Survey Monkey) for those with a current email address. The survey collected socio-demographic and seizure information, as well as respondents' perspectives on living with epilepsy and the use and evaluation of epilepsy specific equipment and services, and health-related quality of life (HRQOL). Ethics approval was gained from Deakin University Human Ethics (2013 – 011) and all participants gave informed consent.

2.1 Data analysis

The analysis was undertaken with the statistical package IBM Corp Released 2013 SPSS Statistics for Windows 22.0. Frequencies, cross tabulations and t-tests were performed as well as correlations. All are presented with the appropriate measure of strength of effects (Gamma, Cramer's V and Cohen's d).

Open-ended responses were transcribed into NVivo 11 and analysed using a basic content analysis approach. Basic content analysis is used to empirically identify

common recurring themes in qualitative data. The data was initially analysed and coded at the sentence level. Codes are then compared and contrasted to allow for categorisation into common themes. Open-ended responses were coded separately by researchers (CW, CP and HC), themes were discussed, and a consensus was reached for final presentation [13].

3. Results

The overall (Wave 4) sample ($n = 393$) had a mean age of 42.02 years ($SD=17.30$) and over half were female (65%). Of these, 330 answered the question relating to ED visits, with 62 missing cases. There was a lower proportion of females in the final sample compared to those who did not respond, but no other significant differences were found between final responders and missing cases.

3.1 Factors associated with ED visits

One hundred and thirty-one (39.7%; missing = 35) had been injured by a seizure in the previous three years. Of these, 92 (70.2%) required hospital treatment during this period and 69 (52.7%) also had an ED admission during the previous 12 months.

One hundred and twenty (36.4%) of the final sample of 330 had been sent for any reason to an ED over the previous 12 months. Mean age of those who attended ED was 43 years ($SD=15.39$, range 10-83) compared to 44.02 years ($SD=16.81$, range 4-81) for those who did not. Differences were not significant ($t=1.901$, $df=327$, $p=.058$; *Cohen's d=.219*, *small effect size*). There were no significant differences in age, gender or education between those who attended an ED and those who did not. The highest proportion to have an ED visit were those under 18 years (52.4%), and the lowest proportion was found for those 65 years and older (20.0%), but this difference was not significant. While there were more than twice the number of females to males in the overall sample, proportions attending an ED were comparable (men 38.05% compared to women 32.5%). Those with a maximum Year 10 (≥ 16 years of age) level of education had the highest proportion of individuals who had visited the ED (Table 1).

There was a significant effect of seizure frequency, employment and subjective prosperity on ED admissions. Those aged 17 and older who were not employed were

significantly more likely to be hospitalised than those employed, and all those having seizures were significantly more likely to be hospitalised than those having no seizures (Table 1). Those who classified their income level as ‘poor’ or ‘very poor’ had significantly higher proportions going to an ED than those who reported they were ‘prosperous’. Effect size ranged from small (employment status), to large for seizure frequency.

Table 1 here

In addition, HRQOL was significantly lower for those who had been injured by a seizure in the previous three years ($M=52.97$, $SD=15.56$) compared to those who had not ($M=61.65$, $SD=15.71$), ($t= -4.12$, $df=244$, $p=0.000$; *Cohen’s $d=.56$, moderate to large effect*).

3.2 Those attending the ED

The following refers to the 120 people who attended an ED in the previous 12 months. Of these, the majority of respondents were from Victoria (50.8%), followed by New South Wales (30.8%); Queensland (8.3%); Western Australia (5.8%); Tasmania (1.7%); and South Australia (0.83%). Two responses were missing (1.7%).

There was an average of 2.3 ED visits by the sample in the previous 12 months with just below 40% going only once, and four people reporting over eight admissions. More than 15% had four or more admissions. This resulted in approximately 272 ED admissions accounted for in the 12 months by 118 people (one outlier omitted and one missing case). More than 70% were kept for observation before being discharged.

Table 2 here

Of the 272 reported admissions, there were 229 (84.2%; missing = 43) descriptions provided of the reason for attending ED. Approximately 50% (n = 59) of respondents with ED admissions had a principal reason of seizure or epilepsy-related problems. This may reflect an underestimation as respondents also reported a number of injuries (e.g., falls, broken bones) that may be related to the occurrence of a seizure. If these are included, then up to 64% (n = 77) may be admitted for epilepsy-related reasons (Table 3). Unfortunately, the possible presence of comorbidities makes it difficult to conclude that admissions not specifically reported as epilepsy-related were related to seizures or injuries caused by seizures as they may have been related to an existing comorbidity.

Table 3 here

3.3 Respondent perspectives of their visits to the ED

Of those who attended an ED for a seizure within the previous 12 months, 11 provided information about the admission and 17 provided information about what they considered would have helped them instead of attending an ED. Another 27 respondents who had not attended an ED in the previous 12 months also provided information and their responses were included, totalling 55 responses. The main themes detailed below relate to loss of autonomy, frustration with poor understanding of epilepsy management, and consequent stigmatisation in ED.

3.3.1 Loss of autonomy and sense of frustration

Participant responses revealed a sense of frustration with their loss of autonomy in being taken to ED. Some reported their clinical needs were not understood, reflecting a poor understanding of epilepsy in the healthcare system. Such incidences were

associated with frustration with the healthcare system or the personal interactions with staff. One respondent gave the example of not being allowed to take the medication she carried in the event of status epilepticus:

“I hate being told I need ER for seizures. The hospital would not give me my seizure meds, so I stayed in status epilepticus for 2 hours when I had my meds with me in my purse”

Loss of autonomy and the associated frustration at being taken to ED often arose as a result of having a seizure in public, and the associated lack of knowledge of bystanders regarding how to manage seizures:

“I hate wasting hospitals’ time with standard seizures. I know when I need to go but others do not.”

“The only reason why my brother ended up in hospital was due to him having a seizure in public and no-one knowing what to do.”

These cases reflect general bystanders calling an ambulance in response to a seizure. The sense that general “others” do not know how to respond to seizures was a consistent theme:

“People [who witness] seizures not knowing what to do”

Some respondents informed those around them when to call an ambulance in order to increase their autonomy and avoid unnecessary hospitalisations:

“Whenever I have a seizure I’ve told my friends and workmates not to ring an ambulance unless I don’t come out of [the] seizure.”

Unnecessary admissions could also undermine autonomy and independence by disrupting the individual’s ability to carry on with their activities. For example, a respondent who was discharged in the early hours of the morning was unable to call friends or family to collect her, heightening the experience of reliance on others.

3.3.2 Dissatisfaction with ED epilepsy management

Frustration at loss of autonomy was compounded when people felt that information they gave ED staff about their condition was ignored. Respondents emphasised that

their lived experience of epilepsy helped them understand whether their seizure was “a standard seizure” or a “normal seizure,” and as a result whether or not they needed emergency treatment. One respondent who had been taken to hospital by ambulance explained this was unnecessary:

“...I didn’t have a cluster of seizures or that my heart slowed down (it has previously after big seizures). My husband and I told the ambulance and the ED doctor I just needed to sleep it off.”

Some respondents experienced felt stigma when their seizures were reportedly confused with being ‘disabled’, having a mental illness or with substance abuse.

“Also have on my notes that I am disabled. Training of staff who think we are drug addicts.”

For some respondents, however, there was recognition that an ED admission might be appropriate depending on the circumstances. Previous experience of significantly lowered heart rate or injury during a seizure, or family experience of sudden unexpected death in epilepsy (SUDEP) prompted respondents to consider the necessity of ED admissions in some instances.

“...I’ve told my family, friends and workmates not to ring an ambulance unless I don’t come out of seizure.”

On those occasions when staff experienced in epilepsy management were not available, respondents felt it was important for staff in attendance to listen to them and take their experience into account.

“[The] Hospital [should] liaise with my Neurologist promptly for advice OR review”

3.3.3 What would have worked instead of being taken to ED

Respondents who had experienced what they considered inappropriate hospital admission or ED attendance suggested better ways to deal with seizures when there was no injury or other identified risks. Going home to rest was a consistent theme, as was self-management of medications and being allowed enough time to recover undisturbed.

“Allow me time to recover and make my own way home.”

“Just to go home to bed”

“Leave me in a quiet spot for twenty minutes. I will come around with a headache.”

Access to medicines was seen as important to recovery and keeping someone out of ED. One person arranged to be taken to the GP. A carer considered “time could have been better spent” administering the person’s medication, also drawing attention to the carer experience of loss of autonomy within the healthcare system.

“Cold wet towel pressed on his forehead helps plus Lamictal, Topamax and Epilum EC500 and Panamax.”

4. Discussion

This study used a mixed methods approach to explore the profile of Australian people with epilepsy who presented to an ED in the previous 12 months. Our sample had a higher rate of hospitalisations (39.7%) compared to previous studies from the UK and Australia, which have indicated hospitalisation rates of up to 18% [1, 3, 14, 15]. One reason for this may be that we included individuals under the age of 18, and children with epilepsy have been found to have higher rates of hospitalisations compared to adults [1, 3]. In line with this, those under 18 years of age had the highest proportion of ED visits albeit not at a significant level. Overall, the mean age of our sample was higher than that of previous Australian studies but the trend towards more hospitalisations for those under 18 compared to those in the 65 years or older group was consistent with the findings of Mitchell et al [3]. Contrary to Mitchell et al.’s findings [3], the hospitalisation rate for EDs in this study was slightly higher for females than males in the current study.

While the Australian Epilepsy Research Register is a national initiative, it should be noted that the majority of respondents were from Victoria and New South Wales, where the register was initiated. As such, our findings may not accurately capture rates of hospitalisations of states or territories in Australia that have a higher proportion of individuals living in rural or remote areas. This is important to consider, given the high rates of hospitalisation among indigenous Australians, which has been linked to suboptimal AED use [16].

Unspecified epilepsy and ‘other generalised idiopathic epilepsy syndromes’ accounted for 70.6% of hospitalisations in Mitchell et al [3]. In this study nearly 54% of ED admissions in a 12-month period were for seizures, or epilepsy-related issues, including status epilepticus. A further >13% of ED admissions were due to complications with epilepsy medication or to possible injuries resulting from seizures, totalling 67.2% of admissions potentially due to epilepsy. Confirming Mitchell et al.’s findings of a disadvantaged hospitalisation status [3], the highest proportion of those hospitalised in our study came from “poor/ very poor” financial situations with lower levels of education.

The extent of ED presentations in this group suggests that further research is required to establish whether it was appropriate care or related to lack of access to primary care including after-hours care and adherence [17]. In line with the findings of Noble et al [18], a general lack of knowledge regarding epilepsy could be a factor in ED presentations. Many of our participants felt that the community, or general “others” lacked an understanding of seizures and their immediate recourse was to call an ambulance. Noble et al also found that people with epilepsy who attended the ED experienced more frequent seizures, higher levels of anxiety, and had lower knowledge of epilepsy and its management themselves [19].

The relationship between seizures, comorbidities, healthcare utilisation and individual wellbeing is complex. For example, people with epilepsy feel that their condition is poorly understood in the community and in the broader health services, which affects their quality of life. A study of health service utilisation in people with epilepsy in Tasmania found that individuals with higher psychological distress had significantly increased attendance at general practitioners, specialists and EDs [20].

The current study demonstrates that many people with epilepsy admitted to ED for a seizure considered that this process led to a sense of disempowerment, where they experienced loss of autonomy and frustration. Respondents considered this to occur more as a result of lack of understanding on behalf of public and health professional than their own management skills. There was strong need identified of finding more appropriate ways to deal with a seizure both in the community and in ED. We acknowledge that, in some instances, this may be difficult to implement. Advice for

someone who witnesses a stranger have a seizure, particularly in the absence of knowledge of any pre-existing medical conditions, is to call an ambulance. Similarly, a qualitative study of UK paramedics' experiences found that paramedics felt most seizure admissions were not clinically necessary, however, due to limited seizure training and lack of background medical information, patients were transported to the ED out of precaution [18]. Having said that, recognition of the individual's lived experience of epilepsy and knowledge of their own treatment needs is important – those living with epilepsy should be part of the solution to improving services.

While those reporting on hospitalisations and ED admissions was a small subset of the overall Wave 4 sample, this study demonstrates that lack of epilepsy knowledge in both the wider community and among health care professionals creates stress for both people with epilepsy and their carers specifically through a process of disempowerment.

5. Conclusion

The importance of patient-centred research and clinical practice is being increasingly acknowledged in the medical field where consumers can identify gaps in services, gaps in both health professional and consumer understanding and seek ways to collaboratively address them [21]. As such, studies that include both quantitative and qualitative data are critical in guiding best practice.

Better understanding of seizures, and their management, where the voice of the person with epilepsy is heard will contribute to appropriate use of ED for people with epilepsy, reducing healthcare costs and contributing to the well-being of people with epilepsy, by meeting their needs better. In addition the special needs of those who are less well-off and those who do not have some of the protective aspects of employment need to be considered in the ED utilisation of those with epilepsy.

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Conflicts of Interest

None to report.

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.

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