

Summary of the Australian Epilepsy Longitudinal Survey - Wave 4

Epilepsy Foundation 2017

Dr Chris Peterson, School of Humanities and Social Science, La Trobe University

Dr Loretta Piccenna, Research Manager, Epilepsy Foundation

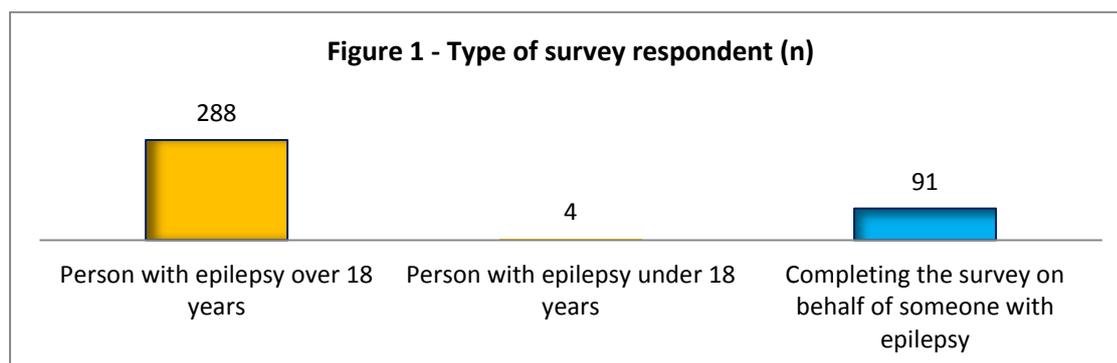
Dr Christine Walker, Chronic Illness Alliance, Victoria

SUMMARY OF THE AUSTRALIAN EPILEPSY LONGITUDINAL SURVEY - WAVE 4

Epilepsy is a lifelong neurological condition estimated to affect over 65 million people worldwide (Ngugi et al, 2011, Bell, Neligan and Sander, 2014). The formal definition of epilepsy endorsed by the International League Against Epilepsy is having at least two unprovoked seizures, or with at least one unprovoked seizure followed by at least two over the next ten years, and/or having a diagnosis of epilepsy (Fisher et al, 2014).

In 2006, the prevalence of epilepsy in Australia was estimated at 268,473 people or 1 in every 73 Australians using data from the 2004 - 2005 National Health Survey (Brown, 2011). The Centers for Disease Control (US) report the prevalence of those with active epilepsy in the US in 2015 was 1.2 per cent of the population (CDC, 2017).

In 2017, there were a total of 1328 eligible participants on the Australian Epilepsy Research Register which is a community-based database. In all 393 of these completed the Wave 4 survey (response rate approximately 30%). Most were people with epilepsy (see Figure 1). The response rate had decreased in comparison to Wave 3 (36%) and Wave 2 (55%), most probably due to people having completing three large surveys in a row.

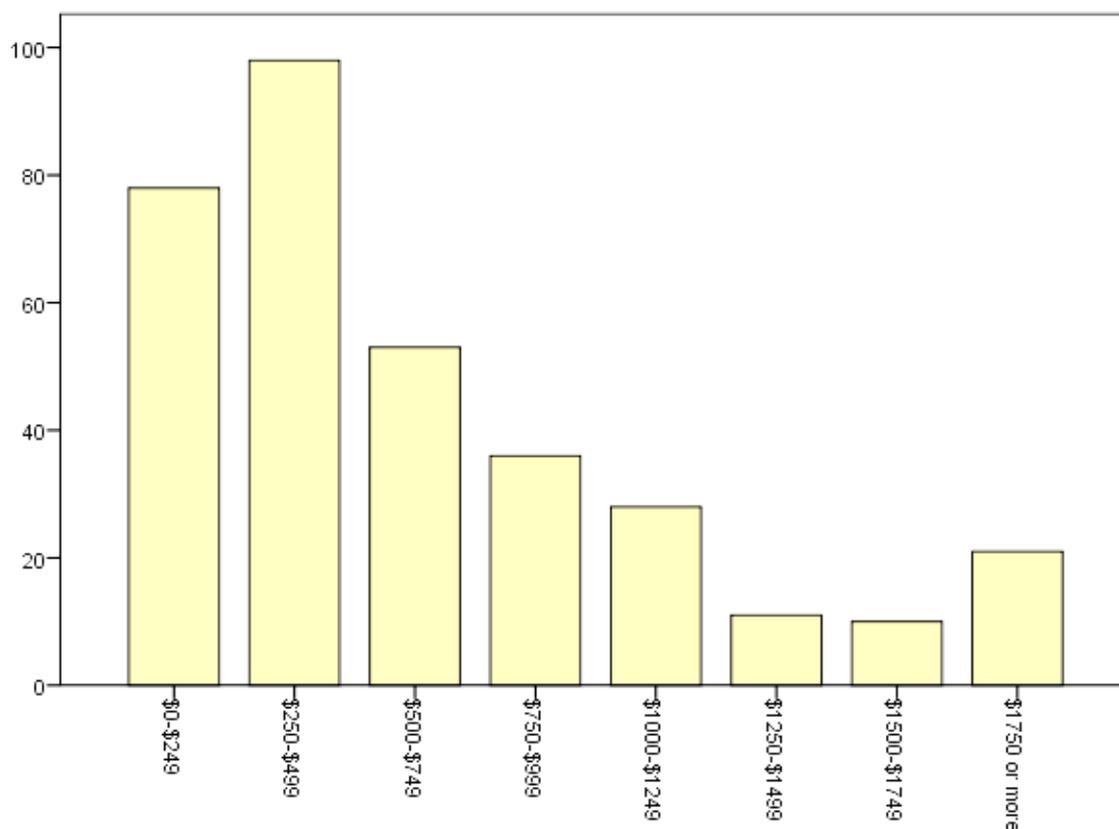


There were two distinct groups in the sample. The first had well controlled epilepsy or epilepsy in remission, and the second largely uncontrolled epilepsy with a greater need for support services.

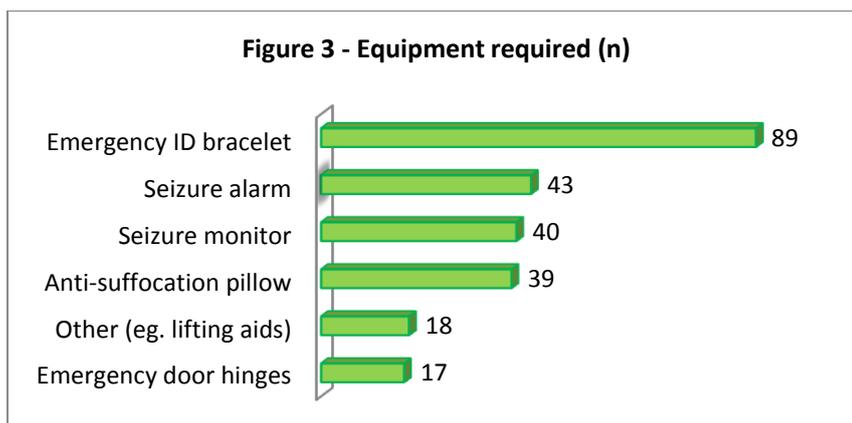
The following were characteristics of the demographics and effects of epilepsy reflecting a level of need in these people.

- Employment and financial difficulty characterise a significant proportion despite high numbers with a university level education. Less than half were in paid employment
- Nearly one third were renting.
- Most received \$250 - \$499 per week in weekly individual income (see Figure 2) and more than one quarter could not pay their *electricity, gas or telephone bills* on time. Therefore there are unmet needs in the epilepsy community, especially for those with uncontrolled epilepsy.

Figure 2 – Weekly individual income before tax



- More than half had experienced *seizures* over the past year; with 14.8% having one or more per month; and 16% having one or more per week.
- 131(36.6%) had been *injured* as a result of a seizure in the past 3 years. 37% of these required hospital treatment
- 53(14.8%) had had *surgery* for epilepsy
- 44.5% said epilepsy affected their *ability to drive* a lot; for 35.5% it affected the *kind of paid work they could do* a lot, and for 33% it affected *their plans and ambitions for the future*
- The average *Quality of life* score in Wave 4 was 56.60 (on a scale of 0-100). This was slightly higher than that measured in Wave 2 (2010)
- The average *Overall health* score was 59.94 (on a scale of 0 – 100) which was lower than that reported in Wave 2 (2010)
- The most needed equipment was *emergency ID bracelets*, followed by *seizure alarms* and *seizure monitors*. Further 39 respondents needed but did not have an *anti - suffocation pillow*, slightly fewer required but did not have *other equipment such as lifting aids*, and fewer *emergency door hinges* (see below)



- A number of respondents did not require education sessions from a variety of sources on *managing risk, self-management strategies and various treatments*. However a similar proportion who accessed them were not satisfied
- The services needed most when initially diagnosed were *a neurologist, advice about treatment options and side effects, a GP and timely access to diagnostic investigations*
- *Psychological assistance* when first diagnosed, *family counselling* and *relationship counselling* were services not available but needed by many
- People felt they needed more support with *transport* (n=84); *attending/making appointments* (n=53); *social activities* (n=52); and *domestic duties* (n=49)
- Partner/spouse provide support for 42.4%; other family/friends for 32.9%; and 10.5% had no one to help

Demographics

Thirty two per cent of respondents had a university qualification. This was similar to the previous Wave 3 (2013) survey (34%), but was much higher than the Wave 2 (2010) survey of 21%. This higher percentage of respondents with a university level of education may be related to the 8% increase in paid employment. Rates of people in paid employment have remained constant over the last 3 years with 47% in paid employment in the current survey and 46% in the previous Wave 3. This rate has increased by 8% since Wave 2 (2010) in which 39% of respondents were in paid employment. This may be reflected by a 3% decrease in the number of respondents receiving a Centrelink benefit in the current survey in comparison to the previous Wave 3 survey (46% vs. 49%). Further strategies or programs are needed to assist people with epilepsy in gaining and maintaining paid employment.

There were two main groups represented in the survey population.

Group 1 - 'Those experiencing difficulties'

Nearly a third of all respondents were renting (32%) suggesting a somewhat mobile population. Weekly individual income for most respondents was low (between \$0 and \$499) and may be a good reason for the proportion of respondents renting. In the previous Wave 3 survey, most respondents reported that they were not able to plan ahead for savings. The current survey revealed many respondents *couldn't pay electricity, gas or telephone bills on time* (27%) and had *asked for financial help from friends and family* (27%). Close to half of the total proportion of respondents had received financial payments from Centrelink (46%). Of those not in paid employment the highest group was

those unable to work due to a disability. This may also be due to a good proportion of respondents who reported always being tired (17%) and worried about having another seizure (12%).

Group 2 - 'The reasonably comfortable'

There were also a group of respondents who fell into the category of being 'reasonably comfortable'. Twenty six per cent had a fully owned home. When asked 'if you needed \$3000 in an emergency...' 35% of respondents said they could easily raise it. This group of respondents may also be as a result of the 8% increase in university level of education (compared to the previous Wave 3 survey), allowing them to gain paid employment and feel reasonably comfortable. A sizable proportion of respondents were living with a partner and/or children (49%) or with other family members (23%) rather than alone (18%). This was supported by the highest total weekly family income category of \$1750 or more indicated by most respondents.

Seizures

The number of respondents in the current survey who had no seizures in the past 12 months was 42%. This was an increase of 6% in comparison the previous Wave 3 (36%) but was similar to Wave 2 (43%), suggesting a population having more well controlled epilepsy or epilepsy in remission. Injuries incurred as a result of a seizure in the past 3 years was reported by 37% of respondents. This was lower than the proportion of respondents in the Wave 3 survey of 40%. Interestingly, in the current survey 7% of respondents reported taking no anti-epileptic drugs which was higher than in the Wave 3 survey (4%) and the Wave 2 survey (5%). This may be related to the increased proportion of respondents having no seizures in the past 12 months. The proportion of respondents taking one anti-epileptic drug was slightly reduced in the current survey (37%) in comparison to the previous Wave 3 survey (40%) but was similar to the Wave 2 survey (35%).

Effects on daily living

The ability to drive and need for *transport* was the most needed activity of daily living. Other unmet needs were engaging in *social activities*, undertaking *domestic duties* and *outdoor maintenance*, *shopping*, and *managing finances*. This lack of need satisfaction all resulted in a significantly lower quality of life (see below).

Those providing most support were partner/spouse (n=119) followed by other friends/family (n=92). In 31 cases there was no one to provide support.

Quality of life and Overall health

Quality of life (QoL) measures items such as worry over seizures, effects of antiepileptic medicines and social function. The average score in Wave 4 for QoL was 56.60 (on a scale of 0-100). This was 2.14 points higher than the score reported by most respondents in the Wave 2 survey (54.36) in which quality of life was also measured (it was not measured in Wave 3). The average overall score for quality of life in the current survey was lower than a recent study of people with drug-resistant epilepsy in the UK, in fact by a score of 9.4 (Risdale et al, 2017). However, their study used an adult version of the QoL inventory and participants were recruited from specialist clinics, not a community population like in the current survey. The Wave 4 study scores were much higher being 12.20 more than those reported in Russia amongst a sample including some previously inadequately treated

patients (Guekht et al., 2007) and 12.30 lower than reported in Malaysia at a tertiary referral centre (Norsa'adah, Zainab and Knight, 2013).

Factors found to predict a higher QoL in people with epilepsy included -

- Being older ,
- Having a higher level of perceived prosperity,
- Having a lower frequency of seizures and a lower number of medications,
- Higher level of overall health and
- Greater satisfaction with information from health professionals.

QoL was found to be substantially lower in –

- People who had depression or anxiety,
- People who needed equipment, aids or modifications but currently did not have them,
- People unsatisfied with most types of online or print information and with education sessions from a range of sources,

One of the factors predicting QoL was age, i.e. being older resulted in a higher quality of life. This may be a result of the period of time that they have had to adjust to their condition since they first started experiencing seizures (an average of 24 years was found for time since diagnosis). Alternatively, it could also be as a result of being in seizure remission or not experiencing frequent seizures due to appropriate control with medication. Having no seizures in the past month was also another predictor that resulted in a higher QoL perceived by people with epilepsy.

The overall average health score was 59.94 (on a scale of 0 – 100). This was reduced by approximately 4 points in comparison to Wave 2 (2010) where the average score reported was 63.95. An analysis of predictors of health revealed that having a benefit entitlement (Centrelink) and not having paid employment predicted poorer health, as did poor seizure control. This reflects the importance of providing paid employment for people with epilepsy to improve their long-term health.

Panel study on Quality of life and Overall health

A longitudinal panel analysis of a small cohort of the same 101 people followed over a long-term period (7 years) revealed that overall QoL in people with epilepsy improved since 2010. QoL for this panel in Wave 4 was 62.52 and in Wave 2 57.82. Hence, there was a difference in scores of 4.70 ($p = 0.002$), showing an overall significant improvement for these same people over the long-term. Further analysis looking at what factors may have influenced and contributed to the changes would be of great benefit for people with epilepsy.

In the panel study of the 101 same people, the average Overall health score was 66.07 and in Wave 2 the score was 69.26. Hence, there was a difference in scores of 3.19 (not significant), showing a decline in health over the long-term.

Equipment and services

People with epilepsy urgently require greater financial support to access equipment such as an *emergency identification bracelet, seizure alarm, seizure monitor, and anti-suffocation pillow*, and to access non-medical services such as *psychological assistance and family counselling*.

Many respondents above the age of 18 did not have an *emergency identification bracelet and seizure alarm* but needed one. In terms of not having an *anti-suffocation pillow* but needing one, the greatest numbers of respondents were under the age of 18 years old. Most respondents who needed seizure alarms and monitors said they could not afford the equipment, suggesting that financial support for aids and equipment is required and should be provided to support people living with epilepsy.

A high proportion of respondents reported not being satisfied with advice on gaining aids and equipment (31%) in comparison to those who were satisfied (26%). This might indicate limited or accurate information provided by companies who produce the aids and equipment, or also that greater training may be required by support workers.

Although there were a sizeable proportion that did not require education sessions from any source on the topics - *managing risk, self-management strategies and various treatments* - there were a similar proportion that accessed them and were not satisfied. This indicates that there is still a need for these sessions to be available for people with epilepsy who may require them.

The type of services needed most principally for a *neurologist and advice about treatment options and side effects*, when initially being diagnosed reflects the importance of multi-disciplinary communication and comprehensive care early on following a diagnosis to ensure appropriate management for the best possible patient outcome. Education on *risks and how to manage them and accurate information about epilepsy support services* were required less when initially being diagnosed. This could suggest that these services are required later on in their life once people have adjusted to their condition, changes which may result due to the condition such as comorbidities (e.g. anxiety or depression) or injuries attributed to their seizures.

A large proportion of respondents felt that *peer support* services were not required which could be reflected by some of the survey population composed of people with well-controlled epilepsy and therefore did not need to access this type of service. Conversely, there were 27% of respondents who were not satisfied with the current availability and quality of peer support services, suggesting that improvements are required.

Almost half of respondents reported that a range of psychological and counselling services were not available but needed. This is an important type of service for people with epilepsy as it is now known that the condition is not just about seizures and their control. Psychiatric comorbidities are common, affecting on average 30 – 50% of people with epilepsy, but they are often underdiagnosed and undertreated (Kanner, 2016). It is therefore important to treat these conditions with psychological services so that people have a better long-term outcome including health, quality of Life and maintaining/remaining in stable relationships for support.

Online or print information about what *government and council services* are available, on *financial assistance, welfare and benefit entitlements* and *superannuation* for people with epilepsy and their families should be improved.

Education from a range of sources requires improvement to address the needs of people with epilepsy and their families and improve quality of life their quality of Life. This includes sessions for *community awareness of epilepsy*, sessions about *risks in epilepsy and how to manage them*, sessions about *symptom management* (e.g. nutrition, exercise, fatigue and continence), sessions on *self-management strategies*, sessions about *treatment options*, and *online education*.

Several epilepsy community support services require improvement to address the needs of people with epilepsy and their families. In particular, *accurate information about epilepsy services*, *education on risks and managing them*, *advise about treatment options and side effects*, and *peer support*.

Open - ended responses

The qualitative analysis of respondents' comments provided more specific insights into the views of supports and services directly from the perspectives of people with epilepsy and their families/friends. Six main themes were identified by respondents relating to access to services and supports –1) 'people don't understand', 2) 'they don't know enough about epilepsy', 3) 'wait times are too long', 4) 'I did not receive the care', 5) 'specialist services are limited (in rural communities)' and 6) 'dealing with my epilepsy'. These themes reflect the gaps in healthcare and support services provided to people with epilepsy. Improvements are required to ensure that the health and quality of life of people with epilepsy is better.

The findings revealed that an improvement in wait times for specialist epilepsy services and more importantly the quality of care provided by health professionals who are outside of neurology such as emergency department staff, pharmacists, nurses, and general practitioners (GPs) are needed. To ensure that patients have the best possible outcomes, it is important to provide a comprehensive, interdisciplinary patient-centred approach. The views of respondents illustrate that there are gaps to this approach, in particular with health professionals outside of neurology who are not equipped with the necessary knowledge to provide good quality care. They suggested that these professions and also staff in workplaces require urgent education. A recent study from the UK has found that paramedics reported seizure management education as 'basic' and would like more additional learning and knowledge to be able to provide the right care (Sherratt et al, 2016). This may reflect similar findings in other health professions as reported by people from the current survey. Several respondents also reported that 'people don't understand' which may be due to the poor levels of knowledge impacting on the quality and provision of care.

Another theme identified was that specialist epilepsy services were limited in rural communities both for medical and community support services. People have to travel to city/metro areas to see their specialist or have certain tests which can be costly and burdensome. A few respondents also commented that they would like a physical centre where they can hold meetings, support groups or access a computer. One potential solution could be setting up and establishing telehealth services in rural and remote communities. The current challenge with telehealth services have been the slow

uptake and fragmentation into the mainstream healthcare system (Bradford, Caffery and Smith, 2017). However, evidence is available to show that telehealth services are beneficial, particularly in improving management of chronic conditions, decreasing costs, reducing inconvenience, improving clinical outcomes and providing peer support, networking and education. A recent study has compared face-to-face consultations and telehealth with patients with epilepsy in Northern Queensland (Adamson, Smit and Costello, 2017). The results of the study were promising showing that patients who received telehealth were satisfied with the quality of care and would prefer this method instead of traveling into the city/metro for their next consultation. Patients who received face-to-face consultations reported greater satisfaction than the telehealth group, however there were greater numbers in this group. The authors concluded that this is a viable model of care for people who are located within regional settings and should be strongly considered to improve care and quality of life.

Conclusion

In summary there were significant numbers with employment and financial difficulties. In addition there were a number of people with unmet needs, especially for those with uncontrolled epilepsy. More than half had experienced seizures over the past year; with 16% having one or more per week. In addition more than one third who had been injured as a result of a seizure required hospital treatment. Nearly one half said epilepsy had a large effect on their ability to drive; and approximately one third said it affected a lot the kind of paid work they could do and it also greatly affected their plans and ambitions for the future.

Quality of life had increased over the past seven years, but overall health had not. Many did not have epilepsy equipment they felt they needed such as seizure monitors and alarms, and nearly half of there could not afford the equipment. Those who did not have needed equipment had significantly lower QoL than others in the sample. Additionally quality of services on being diagnosed could improve with significant effects on QoL, and education from a range of sources, as well as additional information sources could be improved. People needed help mostly with transport, social activities and domestic duties while wait times for services and the lack of services in rural areas were major concerns.

References

Adamson S, Smit M, and Costello C. A survey of patient perceptions of tele-epilepsy services in north Queensland. Poster abstract 80. *Journal of Neurology, Neurosurgery and Psychiatry*. 2017; 88 (5): e1. <http://dx.doi.org/10.1136/jnnp-2017-316074.80>

Bell GS, Neligan A, and Sander AW. An unknown quantity--the worldwide prevalence of epilepsy. *Epilepsia*. 2014; 55(7): 958-62. doi: 10.1111/epi.12605.

Bradford NK, Caffery JL, and Smith AC. Telehealth services in rural and remote Australia: a systematic review of models of care and factors influencing success and sustainability. *Rural and Remote Health* 2017; 16: 3808. Available at - <https://www.ncbi.nlm.nih.gov/pubmed/27744708>

Brown K. Indicators of the social consequences of epilepsy in *Society Behaviour and Epilepsy'* Pinicinhara J and Walker C editors New York Nova Biomedical 2011: pp.17-28.

Centers for Disease Control and Prevention (CDC) *Epilepsy 2017 National Center for Chronic Disease and Health Promotion, Atlanta Georgia.* Available at - <https://www.cdc.gov/epilepsy/index.html>

Fisher R, Acevedo C, Arzimanoglou A et al, A practical clinical definition of epilepsy. *Epilepsia* 2014: 55(4): 475-482.

Guekht AB, Mitrokhina TV, Lebedeva AV et al., Factors on influencing quality of life in people with epilepsy *Seizure*, 2007: 16(2): 128 - 133.

Kanner, A. Management of psychiatric and neurological comorbidities in epilepsy. *Nature Reviews Neurology*. 2015: 12: 106 - 116

Ngugi AK, Kariuki SM, Bottomley C, Kleinschmidt I, Sander JW and Newton CR. Incidence of epilepsy: a systematic review and meta-analysis. *Neurology*. 2011: 77(10): 1005-1012. doi: 10.1212/WNL.0b013e31822cfc90.

Norsa'adah B, Zainab J, and Knight A. Quality of life of people with epilepsy at a tertiary referral centre in Malaysia. *Health and Quality of Life Outcomes*, 2013: 11: 143.

Risdale LL, Wojewodka G, Robinson E et al., Characteristics associated with quality of life among people with drug – resistant epilepsy. *Journal of Neurology* 2017: 264: 1174-1184.

Sherratt FC, Snape D, Goodacre S et al. Paramedics' views on their seizure management learning needs: a qualitative study in England. *BMJ Open* 2017: 7:e014024. doi:10.1136/bmjopen-2016-014024