

Summary of Online Patient Survey on Factors Affecting Quality of Life Among Adults with Epilepsy in Australia

The following report is a short summary of a market research study, which was first published at the Australian and New Zealand Association of Neurologists Annual Scientific Meeting, 21-24 May 2019, Sydney^{1,2}.

Full Study Title—Associations between comorbidities and adverse events of antiepileptic drugs and quality of life: A survey of epilepsy patients in Australia

Thank You

- UCB would like to thank all participants for their time and effort in completing the surveys and sharing their experiences of living with epilepsy.
- This survey contributed to a better understanding of the common side-effects of epilepsy treatment, as well as the experience of other conditions associated with epilepsy. These results will help doctors and other healthcare professionals improve the management of epilepsy in their patients.

Background and Objectives

- The quality of life of people with epilepsy may be affected not only by their experience with seizures, but also other factors such as their treatment situation or mental and emotional state.³
- People with epilepsy may have additional health conditions, such as pain disorders and mental health problems.⁴ Many may also experience unwanted effects from their seizure medications.^{5,6}
- The purpose of this survey was to explore the impact of epilepsy on quality of life, and in particular to better understand the role of medication side-effects and additional health problems among people with epilepsy in Australia.

Methods

- Online surveys were posted on the medication management app, MedAdvisor, and Australian epilepsy patient groups on Facebook.
- To be included in the study, respondents had to be residents of Australia, at least 18 years of age, and report having a seizure disorder or epilepsy.
- The survey questions asked respondents about:
 - The severity of their epilepsy
 - How their epilepsy was managed
 - Whether they experienced unwanted effects from their seizure medication, and
 - Whether they had any additional health conditions.
- A questionnaire known as the Patient-Weighted Quality of Life in Epilepsy Inventory (QOLIE-10-P)⁹ was used to score each respondent's quality of life between 0 (worst) and 100 (best).

Participants

- We received 978 complete responses to the survey. A slight majority (64%) of respondents were female, and the average age was 44 years.
- Respondents to this survey generally had less severe epilepsy than patients surveyed in previous studies, with less frequent seizures, lower number of seizure medications, and higher employment rates on average.^{5,8,9}
- Studies in epilepsy often focus on newly-diagnosed or severe epilepsy, as these patients may be more easily reached through seizure clinics or clinical trials of new medications. However, many people with

epilepsy can have their seizures well-controlled on their first medication.¹⁰ This survey was able to help capture the experiences of this group.

Key Findings

Impact of Additional Health Conditions

- Almost half of the people who responded had one or more mental health problems, such as depression or anxiety. There was also a high rate of pain-related issues, with almost a third of respondents reporting migraine headaches. These rates were higher than in the general population.^{11,12}
- Respondents with the following three types of health disorder had lower quality of life scores on average, compared to those without these conditions. The decreases in quality of life were seen even after we took into account factors such as seizure frequency, age, and employment status.
 - **Mental health problems** were associated with the largest decrease in quality of life. Having depression, anxiety, and/or bipolar disorder lowered quality of life by 23 points on average.
 - **Movement disorder or tremors** and **pain** were each also associated with about a 5-point decrease in quality of life score.

Impact of Medication Side-Effects

- The most commonly reported unwanted effect of seizure medication was sleep problems (89% of respondents), followed by memory problems (68%). Half of respondents reported that their seizure medication had caused unsteadiness or dizziness.
- The following four types of unwanted effects were associated with decreases in quality of life, even after taking into account factors such as depression or anxiety, seizure frequency, employment status, and how long ago epilepsy was diagnosed.
 - **Memory problems** were associated with the largest decrease in quality of life. Respondents who reported having memory problems were estimated to have a 16-point decrease in their quality of life scores compared to those who did not have these issues.
 - **Unsteadiness, sleep problems,** and **gastrointestinal issues** were also linked with lower quality of life, with each side-effect decreasing quality of life score by 5 to 7 points.

Conclusions

- In this group of Australians with epilepsy, including many people with relatively well-controlled epilepsy, mental health, sleep, and memory problems were common.
- Among different types of health conditions and side-effects reported by respondents, mental problems and memory issues were associated with the greatest negative impact on their quality of life.
- To improve the quality of life of people with epilepsy, it is important to consider the impact of mental disorders and medication-related memory problems alongside seizure-related issues.

If you are a person with epilepsy and you believe that you are experiencing a condition or side-effect of epilepsy that is affecting your quality of life, it is important that you seek the help of your healthcare team and discuss any concerns that you have. If you feel that you would benefit from speaking with a counsellor familiar with epilepsy, please contact one of the following services:

- Epilepsy Action Australia: **1300 37 45 37**
- Epilepsy Foundation: **1300 761 487**
- Lifeline Australia: **13 11 14** (24 hours)
 - Online Chat: <https://www.lifeline.org.au/get-help/online-services/crisis-chat> (nightly)
 - Website: www.lifeline.org.au
- Beyond Blue: **1300 22 4636** (24 hours)
 - Online Chat: <https://online.beyondblue.org.au/WebModules/Chat/InitialInformation.aspx> (3pm–12pm AEST, 7 days)

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