

# Summary of Results from Online Patient Survey on Factors Affecting Quality of Life Among Children with Epilepsy in Australia

Full Study Title—Associations between epilepsy comorbidities, antiepileptic drug adverse events and PedsQL™ domains: A survey of paediatric epilepsy patients in Australia

(Poster presented at the 2019 Epilepsy Society of Australia Annual Scientific Meeting in Sydney<sup>1</sup>)

## Thank You

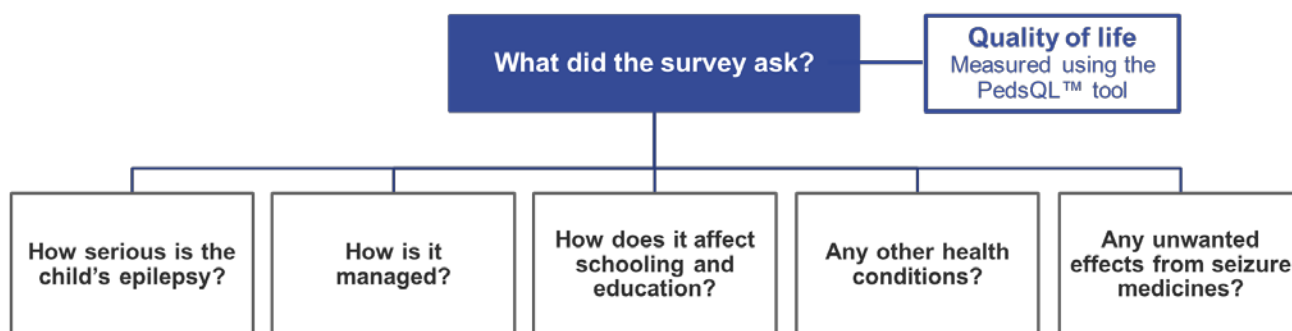
- UCB would like to thank all participants for their time and effort in completing the surveys and sharing their experiences of living with and caring for children with epilepsy.
- This survey contributed to a better understanding of the common side-effects of epilepsy treatment, as well as the experience of other conditions related to epilepsy in children. 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 children with epilepsy may be affected by their experience with seizures, and also by other factors like their social or family situation, or emotional and behavioural issues.<sup>2</sup>
- Children with epilepsy may have additional conditions, such as mental health and brain developmental issues.<sup>3</sup> Many may also experience unwanted effects from their seizure medications.<sup>4</sup>
- This survey aimed to better understand the impact of epilepsy on the quality of life of children with epilepsy in Australia, particularly the role of medication side-effects and additional health problems.

## Methods

- Invitations to participate in online surveys were posted on the medication management app MedAdvisor and on Australian epilepsy patient groups on Facebook. The survey was completed by parents or caregivers of children with epilepsy.
- To be included in the study, the child had to be a resident of Australia, below 18 years of age, and report having a seizure disorder or epilepsy.



- Each child's quality of life was scored using a questionnaire known as the Paediatric Quality of Life Inventory (PedsQL™) Epilepsy Module.<sup>5,6</sup> The higher the score for each area, the better the quality of life.



## Participants

- We received 258 complete responses to the survey: 32 for infants and toddlers, and the rest for school-aged children (5–17 years). We analysed the information from these 226 school-aged children with epilepsy, of whom 53% were male.
- The children in this survey generally had more serious epilepsy than patients surveyed in previous studies—they had more frequent seizures and were taking more seizure medications.<sup>6-8</sup>

## Key Findings

- Average scores for all areas of quality of life were lower than the cut-offs at which doctors might recommend further testing or treatment to help with some of these concerns.<sup>9</sup>

### *Impact of Additional Health Conditions*

- Most people who responded said that their children had **mood and anxiety issues** (82%).
- Almost two-thirds said that their children's peer relationships were affected.
- More than half of the children also faced problems with sleep, and/or learning and development issues.
- We found that some health conditions were linked to lower quality of life in multiple areas. These decreases in quality of life were not related to the seriousness of the children's epilepsy, measured by factors such as seizure frequency.
  - For example, **mood and anxiety disorders** affected quality of life in the areas of mood and behaviour, and also negatively affected the children's learning and memory.
  - Children who faced issues with **social relationships** with their peers also had a lower quality of life in many other areas, including their mood and their ability to carry out daily activities.
  - **Sleep issues** similarly affected almost all areas of quality of life. They had the largest measured negative effect on quality of life.

### *Impact of Medication Side-Effects*

- **Sleep problems** were the most common unwanted effect of seizure medication, reported in 73% of children with epilepsy.
- More than two-thirds said that their child's seizure medication was linked to issues such as speech difficulties, decreased concentration and poorer school results.
- Two-thirds of people who responded said that taking seizure medication was related to hyperactivity, temper tantrums, or other problems with behaviour in their child.
- The following types of unwanted effects were linked with decreases in quality of life, unrelated to the seriousness of the child's epilepsy.
  - **Sleep problems** and **depression** were linked with the largest decreases in quality of life.
  - **Dizziness or blurred sight** affected quality of life in terms of daily activities and sleep.
  - **Behavioural issues** such as aggression and hyperactivity were also linked with lower quality of life in multiple areas.

## Conclusions

- In this group of Australian children with relatively serious epilepsy, the average quality of life was low in all areas, indicating concerns about their overall wellbeing.
- Mood and sleep problems were common, and many of these additional health conditions and side-effects of seizure medications were linked to decreases in multiple areas of the children's quality of life.
- Looking at each condition separately, sleep issues seemed to negatively affect quality of life the most.
- Caregivers of children with epilepsy should consider asking their child's neurologist or paediatrician about any concerns they may have in relation to medication side-effects as well as the effects of other conditions that children with epilepsy commonly experience.

If you are or care for someone with epilepsy and believe that a condition or side-effect of epilepsy is affecting your or their quality of life, it is important to 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](http://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)

## References

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