

The Impact of Epilepsy and its Treatment on Quality of Life from a Parental Perspective

Results of a parent survey, consisting of mixed open and closed questions and completed by participants recruited according to specific criteria via specialist online forums and charity contacts. N=51 (37 had experienced ketogenic diet)

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Objective: Quality of life (QoL) is an important tool in assessing treatment effectiveness. This survey aimed to assess parental perspectives of QoL in relation to epilepsy.

Methods: A survey was constructed consisting of mixed open and closed questions and completed by participants recruited according to specific criteria via specialist online forums and charity contacts. 51 responses were received from parents of children with epilepsy, 37 of which have experienced ketogenic diet (KD)

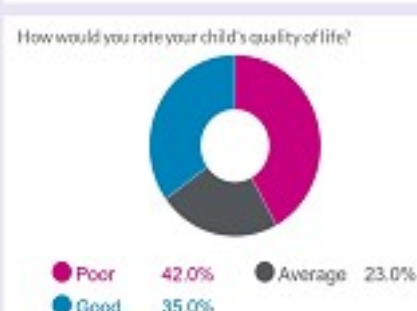
Results:

At diagnosis, treatment goals are focused on stopping or reducing seizures. Minimising impact on QoL for the child is ranked 3rd highest goal. However, 42% of parents of a child with refractory epilepsy describe their child's QoL as 'poor'. Parents define QoL as happiness, enjoyment, social interaction and a sense of 'normality'

Treatment Goals for Parents



Overall Quality of Life Rating



What Quality of Life Means to Parents



QoL is an important treatment goal, and the impact of refractory epilepsy management options on QoL, via side effects, is not equal. Parents tell us that doctors don't see the full extent of these side effects.

% of parents that agree or strongly agree that their child's QoL has improved since beginning the relevant treatment / management option

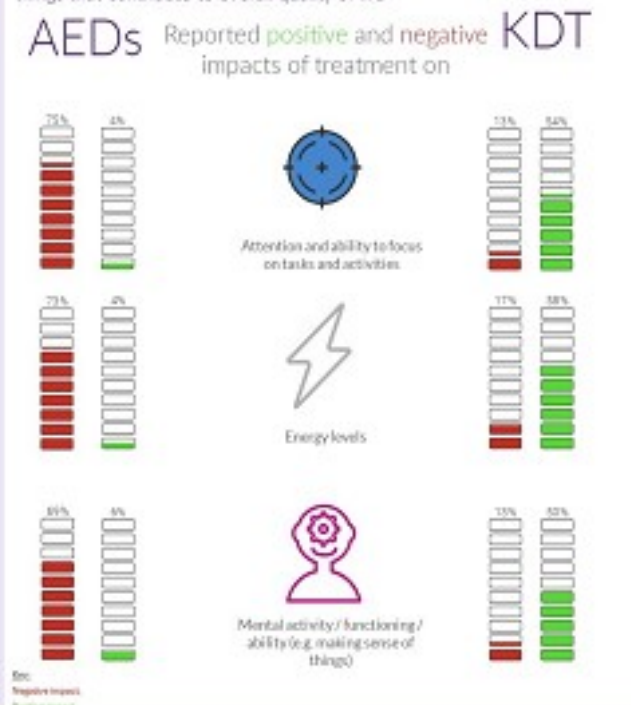


Two thirds of parents see negative side effects with AEDs. By contrast, the KDT positively impacts energy, alertness, communication and focus.

82% of parents agree or strongly agree that "AED side effects impact the whole family"

59% of parents agree that "My doctor doesn't see all the side effects of AEDs"

Two thirds of parents see negative side effects with AEDs. By contrast, the KDT positively impacts energy, alertness, communication and focus - all things that contribute to overall quality of life



Conclusion: Epilepsy is considered a stigmatising illness and the survey showed QoL to be poor in almost half of those surveyed. In the majority of parents surveyed, AEDs were reported to have a negative impact on their child's QoL. When comparing treatment impacts on QoL, just a quarter following AED report improvements. Despite the challenging nature of the KD, almost half of parents in this survey reported an improvement in QoL.

The survey results have limitations as the target population surveyed could have an inherent bias for non-pharmacological treatments and the sample size is small. The survey does serve to highlight the importance of using parent reported outcome measures in research and clinical practice to evaluate treatment efficacy.

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