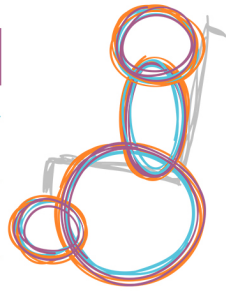


How do adolescents with epilepsy view their quality of life?

childhood
disability
LINK



Summary

The primary aim of this study was to gain a greater understanding of how children and adolescents with epilepsy (specifically, epilepsy that does not respond to medical treatment) perceive their quality of life. To find out, a group of children were asked particular questions in an effort to record what the youths themselves had to say about their quality of life. Results illustrated that all aspects of life (physical, emotional, social and cognitive/academic) were negatively affected by seizures, and that epilepsy negatively affects a youth's identity. Through this study the authors were able to shed light on the degree of distress endured by many youths with epilepsy. Within the physical domain, fatigue, excessive sleep and difficulty getting started on a task were described as barriers to academic and social pursuits. Within the emotional domain, emotional distress including sadness, depression, frustration and anger were heightened due to the unpredictability of their seizures and the loss of control of their bodies. There was a profound sense of isolation within the social domain. The cognitive/academic domain was characterized by learning that was often disrupted. Seizures were perceived as a barrier to normalcy and their sense of being "normal". This study provides direction in terms of what to evaluate when assessing youths' psychosocial needs, and provides evidence for appropriate clinical and community interventions.

What families should know

Parents of epileptic children can, if appropriate, inform teachers of the research-supported possible negative effects of epilepsy on physical, social, emotional and academic functions. For example the child may need a bit of extra effort and patience from the teacher when it comes to getting started on a specific project. Also the teacher should be asked to keep an eye out for social isolation and bullying and do their best to be sensitive to this.

Try to talk to your child about social problems, and create an environment where they feel comfortable approaching you about it. If the problem is severe, consulting a professional may be advisable.

What practitioners should know

Physicians or other professionals may need to carefully evaluate this population to determine if they are in need of any additional resources or supports to enhance quality of life.

Reference

[Elliott, I.M., Lach, L.M., & Smith, M.L. \(2005\). 'I just want to be normal': A qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy & Behavior*, 7, 664- 678.](#)