

Children with epilepsy say their quality of life is better than their parents think

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Children with epilepsy often face multiple challenges — not only seizures but learning, cognitive and school difficulties, side effects from medication, and, not surprisingly, social stigma from their peers.

It's no wonder parents say their [children](#) with epilepsy have a substantially worse quality of life than their other, healthy children. But ask a child with epilepsy about his or her life, and the answer? Not so bad.

Reporting in the current online edition of the journal *Value in Health*, lead study author Dr. Christine Bower Baca, a Robert Wood Johnson Clinical Scholar and a clinical instructor in the UCLA Department of Neurology, and her colleagues found that children with epilepsy say their quality of life is comparable to that of their healthy siblings.

Epilepsy is a common chronic neurological condition that can negatively impact physical, social and psychological function. The burden of epilepsy is large. Overall, approximately 3 million people in the United States have epilepsy, and for half of this population, the disorder first occurred during childhood.

Approximately 45,000 children under the age of 15 develop epilepsy each year. There are many causes of epilepsy in children, including problems with [brain development](#) before birth, lack of oxygen during or following birth, [head injuries](#), tumors, prolonged seizures with fevers, genetics, or infections in the brain.

In the study, researchers assessed 143 children with epilepsy, matching each to a healthy, non-epileptic sibling as a control, and to their parents or guardians. The assessment was done by conducting personal interviews eight to nine years after a child's initial diagnosis, using the Child Health Questionnaire, a generic and well-established measure with both child and parent versions. The average age of the children with epilepsy when interviewed was 12.

The researchers found that parents' ratings of their children's quality of life were significantly lower for their children with epilepsy on 10 of 12 scales measuring such things as behavior, general health, self-esteem and physical function. In contrast, children with epilepsy rated their own quality of life on a par with their siblings.

Why such a difference? One possible explanation, Baca said, is known as the "disability paradox," the idea that having a chronic disease or a disability does not necessarily mean that a person is unsatisfied with his or her life, despite what others may think.

"In this regard, parental perception of their epileptic child may be distorted because of their perception that they have a child that is 'sick,'" Baca said. "Such a distortion could lead to an underestimate of the child's quality of life."

Also, the concerns of a child with epilepsy may differ from those of a parent.

"Children and parents may draw on different values and perspectives to evaluate quality of life and may not be aware of these different perspectives," Baca said.

Recognizing both perspectives is important in assessing outcomes in research studies, Baca noted, particularly in clinical trials evaluating anti-

epileptic medications, and also in trials measuring outcomes after epilepsy surgery. Additionally, quality-of-life evaluations are an essential part of developing clinical disease-management programs that provide comprehensive treatment and education for children with [epilepsy](#) and families. Lastly, Baca said, understanding these potentially different, yet valuable, perspectives is important for developing appropriate support services targeted for children as they make the transition into adulthood.

Provided by University of California - Los Angeles

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