Pediatric health-related quality of life (HRQOL) is a multifactorial construct that covers multiple domains of functioning, such as social, emotional, and school performance. It is not surprising that previous studies have linked seizures and antiepileptic drug side effects to HRQOL. Recent studies have revealed that parent-endorsed stress, worry, fears, and perceived stigma are predictors of parent-reported HRQOL in children with new-onset epilepsy. Ferro conducted a meta-analysis and reported seizure variables, maternal anxiety, presence of a comorbidity, and family socioeconomic status as negative predictors of HRQOL in youth with epilepsy. Duration of epilepsy as a risk factor was moderated by the source of informant (parent vs child). HRQOL is indeed recognized as an important patient-reported outcome, one with modifiable predictors.

In this issue of Neurology, Fayed et al. explore epilepsy-specific quality of life (QOL) related to verbal language skills, mental health symptoms, and peer and parental support in 480 children aged 8 to 14 years. By using structural equation modeling to examine these variables assessed through children’s self-report surveys, the authors demonstrated that social support and mental health in children with epilepsy have strong associations with child-endorsed, epilepsy-specific QOL. Parental support was directly related to epilepsy-specific QOL and also indirectly related through child mental health functioning. A brief measure of verbal intelligence had the strongest association with epilepsy-specific QOL through mental health, and seizure status showed a weak association to epilepsy-related QOL, and only through mental health.

Fayed et al. address relevant practical issues in the evaluation of epilepsy-specific QOL in children with epilepsy and address critical gaps in health care and research, following the recommendations of key epilepsy stakeholders. Other strengths include a large sample size, reliance on self-report data from children themselves, and an epilepsy-specific measure of QOL. One limitation of this study is that only middle to late childhood (8–14 years) is represented, and epilepsy-specific QOL may change across development as the disease course, outcomes, or adherence changes (e.g., reference 1). Because this study relied on youth self-report, findings do not generalize to epilepsy-specific QOL for youth with lower cognitive skills who cannot self-report. Finally, the study sample had good seizure control; therefore, predictors of QOL in youth with more intractable epilepsy may be different.

Although seizure control is the primary goal of epilepsy treatment, it should be obvious that epilepsy health care providers need to look beyond seizures to consider the overall well-being of children and adolescents with epilepsy. Psychosocial factors may result from different aspects of epilepsy, including uncertainty associated with unpredictability of seizures, social isolation, stigma, independence with self-management, and driving restrictions. All of those factors may influence QOL, an outcome endorsed as important, perhaps more salient to patients with epilepsy than seizure control itself. Indeed, school-age children and adolescents with typical development know best their thoughts and feelings regarding many of these variables that require some introspection, which underscores the importance of child-reported, epilepsy-specific QOL. However, the most comprehensive picture of child well-being integrates child report with parent report because there are some domains in which parents are more adept reporters of function (e.g., impulsivity, oppositional behaviors).

Another important research and clinical consideration is the use of instrument or assessment tools to assess or measure QOL in youth with epilepsy. Researchers have used both generic and epilepsy-specific measures. Generic QOL measures allow for cross-disease comparison, while epilepsy-specific measures may be helpful when exploring, for example, antiepileptic drug adverse effects. Of note, the meta-analysis conducted by Ferro did not reveal any differences in predictors of QOL in between generic and epilepsy-specific measures. The Fayed et al. study and the extant literature inform clinical practice in the treatment of epilepsy by suggesting that clinicians should focus on patient-reported outcomes,
such as epilepsy-specific QOL in addition to seizure control and treatment of adverse effects. Early treatment or referral for mental health symptoms or attempts to enhance school, parent, and peer support networks could be crucial to improving outcomes such as epilepsy-specific QOL. In other words, clinicians are encouraged to look beyond seizures and see the child.

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REFERENCES