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Pediatric Quality of Life Inventory (PEDSQL)**

Availability:	Please visit this websites for more information about the instrument: The PedsQL or Home – ePROVIDE™
Classification:	<p>Supplemental- Highly Recommended: Mitochondrial Disease (Mito)</p> <p>Basic: Acute, Moderate and Mild Traumatic Brain Injury (TBI)</p> <p>Supplemental: Cerebral Palsy (CP), Duchenne Muscular Dystrophy (DMD), Epilepsy, Friedreich’s Ataxia (FA), Headache, Spinal Muscular Atrophy (SMA) and Epidemiology TBI</p> <p>Exploratory: Myotonic Dystrophy (DM)</p>
Short Description of Instrument:	<p>Description: Developed in the US in 1998.</p> <p>The PedsQL 4.0 Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model covers 4 domains: physical (8 items), emotional (5 items), social (5 items) and school (5 items). It provides a total scales score from 23 items, of which 8 are for physical health summary score and 15 are for psychosocial health summary score.</p> <p>The instrument takes 4 minutes to complete and is translated in multiple international languages including broadcast Spanish. It is usable for parents/guardians of children between the ages of 2 to 18 years (in 4 age groups) and child versions are available for all age groups except the 2-4 years old.</p>
Scoring:	<p>Scoring:</p> <p>0-100 scale with scores near 0 representing lower QOL and scores near 100 representing higher QOL. Individual subscale scores can also be calculated for each of the four areas of functioning: physical, emotional, social, and school. To score, items are transferred to a 0-100 scale, ie, 0=100, 1=75, 2=50, 3=25, 4=0. Scores are then averaged to obtain a final score between 0-100.</p>

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Rationale / Justification	<p>Particular Features: PedsQL Disease-Specific Modules are available for asthma, arthritis, cancer, cardiac disease, and diabetes. There is no module at this time for epilepsy.</p> <p>Psychometric Properties: Reliability: Over all 23 multi-item scales had internal consistency reliabilities averaging 0.80. The total scale score had $\alpha=0.88$ for child and $\alpha=0.90$ for parent report. Validity of scales: Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition. Sensitivity to Change: One article showed that children with epilepsy had impairments in HRQOL but there were no differences in the parent proxy scorings between a single seizure population and a newly diagnosed untreated population. Therefore it is likely that the PedsQL will not be sensitive to change as a result of treatment of epilepsy. Relationships to other variables: One article showed that HRQOL in siblings of children with intractable epilepsy may also be lower than average.</p> <p>Strengths and weaknesses: Strengths: Short and easy to complete. Widely used and validated in US. Has many translations. Weaknesses: No epilepsy module. It is an overall quality of life tool that does not focus on either epilepsy or its treatment. Few studies in pediatric epilepsy used this tool (one in the German version).</p> <p>Limitations: Nothing specific noted in publications on the studies listed above, although a reliable mitochondrial disease-specific module does not exist. PedsQL 4.0 has been described as one of the three available general measures of QOL in childhood and adolescence with adequate psychometric properties for application in clinical research. (NINDS Headache CDEs)</p> <p>Advantages: Short and easy to complete . Broad measurement of function collected in under 4 minutes</p>
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References:	<p>Key Reference:</p> <p>Varni JW, Seid M, Kurtin PD. PedsQL 4.0: Reliability and validity of the pediatric quality of life inventory Version 4.0 generic core scales in healthy and patient populations. <i>Med Care</i>. 2001;38(8):800–812.</p> <p>Felder-Puig R, Frey E, Proksch K, Varni JW, Gadner H, Topf R. Validation of the German version of the Pediatric Quality of Life Inventory (PedsQL) in childhood cancer patients off treatment and children with epilepsy. <i>Qual Life Res</i>. 2004;13(1):223–234.</p> <p>Modi AC, King AS, Monahan SR, Koumoutsos JE, Morita DA, Glauser TA. Even a single seizure negatively impacts pediatric health-related quality of life. <i>Epilepsia</i>. 2009;50(9):2110–2116.</p> <p>Wood LJ, Sherman E, Hamiwka LD, Blackman M, Wirrell E. Depression, anxiety, and quality of life in siblings of children with intractable epilepsy. <i>Epilepsy Behav</i>. 2008 13(1):144-48.</p> <p>Varni JW, Limbers CA. The pediatric quality of life inventory: Measuring pediatric health-related quality of life from the perspective of children and their parents. <i>Pediatr Clin North Am</i>. 2009;56(4):843–863.</p> <p>Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. <i>Ambul Pediatr</i>. 2003;3(6):329–341.</p>
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