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Pediatric Quality of Life Inventory (PEDSQL)**

Availability	<p>Please visit this websites for more information about the instrument: PedsQL or ePROVIDE</p>				
Classification	Pain Impact/ Interference	Children ages 5–18 years, specific to SCD.	PedsQL Pain Impact SCD module (children)	Core	Preferred if the study population are children. Parent proxy measures are available for ages 2–18 years.
	Pain: Mixed	Children ages 5–18 years, specific to SCD	PedsQL Pain and Hurt, SCD modules	Core	Preferred if the study population are children. Parent proxy measures are available for ages 2–18 years.
	Emotional Impact of SCD	Children, specific to SCD	PedsQL, SCD Module Emotions	Supplemental, Highly Recommended	
	Emotional Impact of SCD	Children, specific to SCD	PedsQL, SCD Module Worrying	Supplemental	
	Fatigue	Children with SCD	PedsQL Multidimensional Fatigue Scale	Core	
Short Description of Instrument	<p>Description: Developed in the US in 1998, 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>
<p>Comments/Special Instructions</p>	<p>N/A</p>
<p>Scoring and Psychometric Properties</p>	<p>Scoring: The instrument contains 23 items encompassing four areas: physical, emotional, social, and school. Participants respond on a Likert scale from 0 to 4. Items are reverse scored and linearly transformed to a 0 to 100 scale, with higher converted scores indicating better HRQL. The instrument provides four domain scores, two summary scores (physical and psychosocial functioning), and a total HRQL score.</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, i.e., 0=100, 1=75, 2=50, 3=25, 4=0. Scores are then averaged to obtain a final score between 0-100.</p> <p>Psychometric Properties: Well-standardized and validated, good reliability and sensitivity to change, good correlations with other standardized measures of disease severity in disease-specific modules.</p> <p>Reliability: Over all 23 multi-item scales had internal consistency reliabilities averaging 0.80. The total scale score had a=0.88 for child and a=0.90 for parent report.</p> <p>Validity of scales: Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition. Headache specific data is also supportive of the reliability (internal consistency and test-retest) and validity (criterion related, convergent, known-groups, and responsiveness to intervention) of the PedsQL 4.0 within a pediatric headache sample.</p>
<p>Rationale/Justification</p>	<p>Particular Features: PedsQL Disease-Specific Modules are available for asthma, arthritis, cancer, cardiac disease, and diabetes.</p> <p>Limitations:</p>

	<p>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). It is an overall quality of life tool that does not focus on either epilepsy or its treatment.</p> <p>Advantages: PEDSQL is short, easy to complete, and is widely used and validated in US. It also has many translations. Lastly, it is a broad measurement of function collected in under 4 minutes</p>
References	<p>Key Reference: 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>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>