

## **Pediatric Quality of Life-Family Impact Module (prepared by Louise Fleming, PhD, MSN-ED, RN)**

**Title of Measure:** Pediatric Quality of Life-Family Impact Module

**Website:** <https://eprovide.mapi-trust.org/instruments/pediatric-quality-of-life-inventory-family-impact-module>

**Reference for original article(s) describing how the measure was developed and tested:**

- Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL: measurement model for the pediatric quality of life inventory. *Medical care*, 37(2), 126–139. <https://doi.org/10.1097/00005650-199902000-00003>
- Varni, J. W., Sherman, S. A., Burwinkle, T. M., Dickinson, P. E., & Dixon, P. (2004). The PedsQL Family Impact Module: preliminary reliability and validity. *Health and Quality of Life Outcomes*, 2(55). <https://doi.org/10.1186/1477-7525-2-55>

**Purpose/Background:** The Peds QL-FIM was designed to measure parent self-reported perceptions of the impact of the condition on their physical, emotional, social and cognitive functioning; communication; and worry. The measure also examines parent-reported family daily activities and family relationships (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). In prior studies, the Peds QL-FIM internal consistency reliability coefficients have ranged from .82-.97 (Varni et al., 2004).

**Psychometrics:**

- Scale internal consistency reliability was determined by Cronbach's coefficient alpha scores and construct validity was done using the known groups method comparing scores between families in which a child had a chronic condition living at home versus families where the child with the condition was living in a long term care setting
- Cronbach's alpha scores exceeded .70 for both groups- initial testing was limited b/c of small sample size

**Scoring procedure:**

- Can be used alone or with PedsQL measure
- 36 items with 8 scales measuring:
  1. physical functioning (6)
  2. emotional functioning (5)
  3. social functioning (4)
  4. cognitive functioning (5)
  5. communication (3)
  6. worry (5)
- Two additional scales examining parent-reported family functioning:
  7. daily activities (3)
  8. family relationships (5)
- 5-point response scale is used (0- not at all a problem; 1-almost never a problem; 2-sometimes a problem; 3-often a problem; and 4-almost always a problem)
- Items are reverse scored and linearly transformed to a 0-100 scale (0=100; 1=75; 2=50; 3=25; 4=0)
- Higher scores indicate stronger family functioning
- Total scale is the sum of all 36 items divided by the number of items answered
- The parent HRQoL summary score is comprised of scales 1-6; the family functioning summary is scales 7 and 8

**Norms/Comparative Data:** In a community sample of over 900 parents of children 2-17 years old, The internal consistency reliability of all scales of the PedsQL-FIM showed exceptional results. The measure's current structure was supported by confirmatory factor analysis. It exhibited the anticipated correlations with established measures of anxiety, depression, child

health-related quality of life (HRQOL), and the number of chronic conditions acknowledged. Furthermore, independent t-tests demonstrated that the measure effectively distinguishes between parents who reported having a child with a chronic condition and those who did not, confirming its discriminant validity.

- Medrano, G. R., Berlin, K. S., & Hobart Davies, W. (2013). Utility of the PedsQL™ family impact module: assessing the psychometric properties in a community sample. *Quality of Life Research*, 22, 2899-2907.

**Populations the measure has been used with:**

- Families of children with ADHD
- Families of children with cancer
- Families of children with chronic diseases
- Families of children with chronic pain
- Families of children with sickle cell disease
- Families of children with asthma
- Families of children with non-specific chronic diseases
- Families of children with congenital adrenal hyperplasia

**Languages the measure is available in:**

- Chinese
- English
- Malaysian
- Portuguese

**Strengths and Limitations of the measure:**

- Results of studies may be dependent on specific conditions
- Time of survey related to time of treatment should be considered
- Small sample size can be problematic
- Administration of measure may vary (for example, if the questions are given via interview due to those with literacy concerns)

**References for articles that include a discussion of strengths and limitations of the measure:**

- Scarpelli, A. C., Paiva, S. M., Pordeus, I. A., Varni, J. W., Viegas, C. M., & Allison, P. J. (2008). The pediatric quality of life inventory (PedsQL) family impact module: reliability and validity of the Brazilian version. *Health and Quality of Life Outcomes*, 6(35). <https://doi.org/10.1186/1477-7525-6-35>
- Jastrowski Mano, K. E., Khan, K. A., Ladwig, R. J., & Weisman, S. J. (2011). The impact of pediatric chronic pain on parents' health-related quality of life and family functioning: reliability and validity of the PedsQL 4.0 Family Impact Module. *Journal of Pediatric Psychology*, 36(5), 517–527. <https://doi.org/10.1093/jpepsy/jsp099>
- Chen, R., Hao, Y., Feng, L., Zhang, Y., & Huang, Z. (2011). The Chinese version of the Pediatric Quality of Life Inventory™ (PedsQL™) Family Impact Module: cross-cultural adaptation and psychometric evaluation. *Health and Quality of Life Outcomes*, 9(16). <https://doi.org/10.1186/1477-7525-9-16>

**References for articles by IFNA researchers and others who have used the measure**

- Al-Gamal, E., & Long, T. (2016). Psychometric properties of the Arabic version of the PedsQL Family Impact Scale. *Journal of Research in Nursing*, 21(8), 599-608. [10.1177/1744987116670204](https://doi.org/10.1177/1744987116670204)
- Al-Gamal, E., & Long, T. (2017). The Psychometric Properties of an Arabic version of the PedsQL Multidimensional Fatigue Scale Tested for Children with Cancer. *Comprehensive child and adolescent nursing*, 40(3), 188–199. <https://doi.org/10.1080/24694193.2017.1316791>

- Fleming, L., Knafl, K., Knafl, G., & Van Riper, M. (2017). Parental management of adrenal crisis in children with congenital adrenal hyperplasia. *Journal for Specialists in Pediatric Nursing : JSPN*, 22(4), 10.1111/jspn.12190. <https://doi.org/10.1111/jspn.12190>
- Limbers, C. A., Ripperger-Suhler, J., Boutton, K., Ransom, D., & Varni, J. W. (2011). A comparative analysis of health-related quality of life and family impact between children with ADHD treated in a general pediatric clinic and a psychiatric clinic utilizing the PedsQL. *Journal of Attention Disorders*, 15(5), 392–402. <https://doi.org/10.1177/1087054709356191>
- Matziou, V., Vlachioti, E., Megapanou, E., Ntoumou, A., Dionisakopoulou, C., Dimitriou, V., Tsoumakas, K., Matziou, T., & Perdikaris, P. (2016). Perceptions of children and their parents about the pain experienced during their hospitalization and its impact on parents' quality of life. *Japanese Journal of Clinical Oncology*, 46(9), 862–870. <https://doi.org/10.1093/jjco/hyw074>
- Meyer, R., Godwin, H., Dziubak, R., Panepinto, J. A., Foong, R. M., Bryon, M., Lozinsky, A. C., Reeve, K., & Shah, N. (2017). The impact on quality of life on families of children on an elimination diet for Non-immunoglobulin E mediated gastrointestinal food allergies. *The World Allergy Organization Journal*, 10(1), 8. <https://doi.org/10.1186/s40413-016-0139-7>
- Sikorová, L., & Buzgova, R. (2016). Associations between the quality of life of children with chronic diseases, their parents' quality of life and family coping strategies. *Central European Journal of Nursing Midwifery*, 7(4), 534-41. <https://doi:10.15452/CEJNM.2016.07.0026>