

Health Related Quality of Life in Children with Intestinal Failure

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Background: The life expectancy of infants with intestinal failure has increased in the past decade. Now, children with intestinal failure survive well into their childhood years. However, data on their health-related quality of life (HRQOL) are lacking. We hypothesized that HRQOL would be lower among children with intestinal failure and their families compared to that of healthy children.

Methods: We performed a cross-sectional study of HRQOL of children and their parents enrolled in the outpatient intestinal rehabilitation program at Seattle Children's Hospital using the PedsQLTM 4.0 Generic Core Scales parent-proxy report and the Family Impact Module questionnaires. We compared PedsQLTM scores with previously published normative data and examined associations between PedsQLTM scores and patient demographics and clinical characteristics. Parents were asked two open-ended questions pertaining to the suitability and completeness of the PedsQLTM to assess their and their child's HRQOL.

Results: Parents of 23 children with intestinal failure completed the survey. Parents reported significantly lower total PedsQLTM scores for children aged 1 to 2 years (mean difference = 13.16, $p=0.003$) and 3 to 4 years (mean difference = -17.63, $p=0.001$), compared to norms for healthy children. Scores were also lower for children younger than 1 year (mean difference = -6.43) and children aged 2 to 3 years (mean difference = -11.96), though neither test reached statistical significance. The Family Impact Module

scores of parents were similar to existing reports by parents caring for children with chronic illnesses (mean difference = -1.19, $p=0.852$). No measured demographics or clinical characteristics were associated with HRQOL in this sample. The majority of parents (65%) said the PedsQLTM failed to address important impacts of intestinal failure on children and their families. In particular, the PedsQLTM did not address challenges parents face nurturing their child or supporting their child's attainment of developmental milestones.

Conclusions: Children with intestinal failure and their parents have a decreased HRQOL compared to healthy children as measured by the PedsQLTM. The majority of parents identified additional challenges associated with intestinal failure that affect a child's and family's HRQOL. A disease-specific module or separate HRQOL questionnaire is needed for a more comprehensive assessment of the HRQOL of children with intestinal failure and their families.

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