

Measuring and monitoring quality of life in children and youth: a brief commentary

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Measuring and monitoring the health-related quality of life (HRQL) in children and youth continues to increase in importance to both researchers and decision makers. Such interest is evidenced by large-scale cooperative programmes such as KIDSCREEN¹ and the inclusion of validated measures in randomised clinical trials throughout North America and Europe.

As recently as 1995, however, only 12 of 505 abstracts accepted at the Annual Conference of the International Society for Quality of Life Research were pediatric-focused.² Last year, 15 abstracts focused on specific measures for children while an additional 14 dealt with measurement issues such as concordance between parent and child reports and the influence of socio-demographic factors on HRQL.³ The intervening six years have produced a noteworthy selection of published generic and condition-specific measures for children and the identification of child-specific conceptual and methodological issues that may impact study design and interpretation of findings²⁻⁹.

While these advances are laudable, skeptics may question the need to assess the quality of children's health given the relatively low prevalence of pediatric chronic health conditions and/or disease in developed countries. As we have come to appreciate, however, health is more than just a constellation of symptoms or the simple presence or absence of disease. As noted by the WHO, it is "a state of complete physical, mental and social well-being".¹⁰

Thus, for children and adolescents, health is not just about the ability to engage in varying levels of physical activity. It's about identifying with others, doing things that peers can do, feeling accepted, having friends, performing well in school or excelling on the playing field. For parents, it's about days missed from work and school and the degree to which their child's physical and psychosocial health impacts life at home. For policymakers and health-care providers it's about the

long-term and latent affects of disease in these pivotal areas of a child's life¹¹⁻¹⁴ and the degree to which children may be limited or at risk.¹⁵

The complexity in defining and measuring HRQL in this special population remains an ongoing challenge; the most compelling issue being the discrepancy between children's perceptions of health and that of their parents.⁴⁻⁷ I remember when my oldest daughter, now 18, was in elementary school. As we struggled to get her asthma under control, she routinely missed between 8-10 school days each year. We were concerned that lengthy absences would compromise her learning experience and used her final marks as a way to gage "success". Being sick was upsetting to her, but the full emotional implications of what these absences might mean to her personally was not something we considered. We were just thankful that she was able to manage her studies and achieve noteworthy grades. At the end of her 6th grade year she taught us an invaluable lesson about differences between children and parents when she rushed in holding her report card high in the air and exclaimed, "Mom, isn't this the best! I only had 3 absences all year!" As the field of HRQL matures, we must continue to honour what children have to say - even if it differs from the perceptions of their parents.

Extensive school-based studies such as those conducted by Waters and her colleagues,¹⁶ international collaborations such as PRINTO¹⁷ and public health projects such as KIDSCREEN, DISABKIDS¹⁸, enrich our understanding of children's health at a macro level and provide new insights into their everyday functioning and well-being. Studies such as these enable us to view this special population with a wider and more comprehensive perspective and build the foundations necessary for answering key questions about the ongoing impact of public policies, interventions, therapies, and treatments.

Augmenting these efforts are applied outcomes programmes such as those among specialists in the U.S.-initiatives that dimension the impact of therapies and treatments at the individual patient level as well as nationally^{19,20}. Whether its decision-making across countries or within families, measuring the health-related quality of life for children and youth

continues to establish itself as a pivotal outcome – one that will grow in stature and prominence as we continue “to strive, to seek, and to learn” and honor the children within each of us.

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