



EDITORIAL

Advances and challenges in the measurement of health related quality of life in the child and adolescent population[☆]



Avances y retos en la medida de la calidad de vida relacionada con la salud en la población infantil y adolescente

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Health-related quality of life (HRQoL) is a multidimensional concept which can be used as a patient-reported outcome (PRO) to document how individuals perceive their own health and well-being. It aims to encompass every facet or dimension of health. In the paediatric population, HRQoL measures take into account the ability to fully participate in age-appropriate physical, social and psychosocial activities and functions.

In childhood and adolescence, HRQoL is useful to describe the health of a population and compare subsets with specific characteristics (socioeconomic, regional, etc.). In paediatric clinical practice, the assessment of HRQoL may provide useful information on a patient's health status, help assess the effects of different treatments and the severity of disease, and facilitate clinical decision-making.

This issue presents 2 studies on paediatric HRQoL. The first evaluates the validity of an HRQoL instrument in

children aged 3–6 years¹ while the second assesses HRQoL in a group of children aged 8–14 years with attention-deficit hyperactivity disorder (ADHD) and compares it to HRQoL in controls without ADHD.² Both collected responses from proxy reporters (parents), although the self-reported responses of the children have also been reported for the latter study.³

These studies illustrate some of the issues and challenges currently faced by those wishing to assess HRQoL in children and adolescents. The first challenge is that of measuring HRQoL in a very young segment of the population. In particular, the question arises as which aspects of life are most important to the very young, such as family, peers, the school environment and the community. Furthermore, measures intended for use in this population must aim to capture the child's subjective perception of their performance on those "dimensions" of HRQoL.

Parent versions of paediatric HRQoL measures are typically used as an alternative means of assessing health status in the youngest individuals. In the case of the Kiddy-KINDL, a self-report version is available although, as reported by Orgiles et al.,¹ there is no clear evidence that most self-report measures are reliable and valid in these age groups. The development of observer-reported outcome (ObsROM) measures has therefore been recommended for this age

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group, as well as a more thorough analysis of the agreement between self- and parent-reports.⁴ In recent years, several ObsROM measures have been developed for administration to parents, including instruments to assess nausea in children aged less than 5 years, respiratory problems in children aged under 2 years with bronchiolitis, and gastroesophageal reflux in children aged less than 18 months.

Similarly, the study by López-Villalobos et al.^{2,3} illustrates other current issues related to the use of HRQoL tools in paediatric populations; for instance, how they can or should be used to assess specific diseases in paediatric clinical practice, and whether it is necessary to obtain both the responses of children and parents (or other proxy reporters) when data can be obtained from the subjects themselves. The use of HRQoL measures in paediatric clinical practice is growing in importance, especially in relation to specific health problems such as the one reported in this article, or in patients with chronic diseases, such as type 1 diabetes. Monitoring HRQoL can help detect problems affecting children that may impact a treatment and its outcomes, and can aid in the search for alternatives to improve patient health. With regard to the data source, obtaining both proxy- and self-reports contributes additional information, and allows a greater understanding of the level of agreement between reporters. Previous studies have found variable levels of agreement between self- and proxy reports. In general, agreement is greater the younger the child is, the worse the patient's condition, and the more "observable" the analysed dimension.

One of the most significant methodological limitations in the creation and development of an instrument to assess HRQoL in the paediatric population is the specific age range the instrument is to target and determining the youngest age at which children can provide valid and reliable responses to a self-administered questionnaire or in an interview. It is important to ensure that the instrument is adequately designed for the target age range. The factors to consider include the use of health-related vocabulary, reading level, response scales, recall period, instrument length, the use of pictorial representations (if any), formatting details, administration approaches, and electronic data collection.⁴

Another challenge in the development of paediatric HRQoL measures involves the processes of growth and physical, cognitive, intellectual and emotional development in the child, which are ongoing. It is difficult to capture the positive or negative aspects of that development, and its impact on quality of life, over a broad age range. For that reason, cognitive interviews aimed at generating content for HRQoL measures should be performed with the members of the measure's target population (the children themselves, parents, health care providers etc.), and content validity should be assessed in narrow age bands.

The field of paediatric HRQoL has grown in recent years. A review of the literature identified 96 instruments to measure child and adolescent HRQoL published by 2006. Between 2017 and 2018, at least 40 additional questionnaires were published, along with over 1500 studies on paediatric HRQoL and 10 systematic reviews on HRQoL in specific conditions such as coeliac disease, cancer, paediatric neurosurgery or cerebral palsy, among others.

Other recent advances include the development of new instruments using computerised adaptive testing and item banks. These advances improve the quality of the data obtained and save time in the administration of the questionnaire. However, they also pose methodological problems that have yet to be resolved, and are of limited usefulness and difficult to interpret in the assessment of individual subjects. We should take advantage of the fact that children are gaining access to information and communication technologies at increasingly early ages, along with their exposure to screens (factors with a negative impact on other areas, such as health-related behaviours), to incorporate PRO measures using this medium, and assess the reliability, validity and usefulness of such measures in clinical practice and in the evaluation of health care interventions.

In short, in recent years paediatric HRQoL has acquired a growing importance. Future challenges include evaluating the use of HRQoL measures in everyday clinical practice and facilitating the interpretation of their results to offer children the opportunity to express how they perceive their health and quality of life.

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