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"Mind the gap". Exploring Parent-Child Agreement in the Measurement of Child Health-Related Quality of Life - A Mixed Methods Approach

The use of child-specific generic preference-based measures (PBMs) such as the EQ-5D-Y-3L and CHU9D to assess Health-Related Quality of Life (HRQoL) facilitates the derivation of utilities for cost-utility analyses and quality assessment in pediatric populations. However, the challenges of self-assessment due to developmental and cognitive constraints often require proxy reports to complement or replace child self-reports. This mixed-methods study aimed to: 1) Investigate parent-child agreement for the child's HRQoL using generic PBMs, and 2) Assess children's comprehension of HRQoL dimensions using a qualitative think-aloud approach within a community based sample of children (aged 6-12 years) and parent dyads from South Australia. The findings indicated a consistent yet low level of agreement between child and proxy assessments, with notably poor concordance in psychosocial-related dimension such as "feeling worried, sad, or unhappy" of the EQ-5D-Y-3L. In contrast, the CHU9D showed high agreement levels in dimensions like "sadness" and "pain". This study revealed that younger children, particularly those aged 6-10 years, struggled with understanding and accurately reporting HRQoL dimensions, often leading to significant discrepancies with parental proxy reports.

These discrepancies were not always indicative of actual health impairments but rather reflected challenges in comprehension and interpretation.

Learning objectives:

- The assessment of pediatric HRQoL is complex, particularly in subjective domains that are not directly observable, and highlight the impact of age on children's understanding of these dimensions.
- There is a need for the development and validation of age-appropriate HRQoL measures and call for ongoing research to enhance the validity of both self and proxy reports.

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C2E2 Spotlight is held monthly on Mondays from 12:00 pm to 1:00 pm. To attend in-person or virtually please contact pamela.lee@ubc.ca.