Let us talk: A deliberative approach to improve inter-rater agreement in the assessment of Health-Related Quality of Life in children.

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Abstract

Objective: The measurement and valuation of health-related quality of life (HRQoL) in children is fundamental to quality assessment and the economic evaluation of paediatric health and social care services. This study compared the inter-rater agreement between child-self and parental-proxy HRQoL ratings (overall and domain level) and assessed the impact of a deliberation approach on improving agreement using the EQ-5D-Y-3L.

Methods: A community-based sample of child (ages 6-12 years) and parent dyads (N=85) participated in the study. For the first stage assessment, the child completed the EQ-5D-Y-3L independently of the parent who completed EQ-5D-Y-3L-Proxy 1 and Proxy 2 versions. Approximately half of the sample (N=42) dyads were invited to take part in the second stage deliberation, in which they were encouraged to discuss their responses with each other, with the option of revising their initial responses where divergences were evident. The HRQoL values were calculated using the Australian adult EQ-5D value set. The inter-rater agreement was determined using concordance correlations coefficients (CCCs) for the overall values whilst the level of agreement for the HRQoL domains were evaluated using Gwet's agreement coefficient (AC1). Child-self and proxy-rated differences in overall HRQoL across subgroups (such as child age, child gender, parent gender, child self-rated general health, presence of long-term conditions and household income) were evaluated using Wilcoxon signed-rank test.

Results: All child-parent dyads successfully completed the first stage assessment. The value-weighted EQ-5D-Y-3L profiles using Proxy versions 1 and 2 were identical, however, significantly different (diff= -2.14, p=0.02) EQ VAS scores were reported from the two proxy perspectives. No significant differences were found in the overall self and proxy values except for the subgroup with boy-children (diff= 0.02, p=0.05) and when children self-rated their general health as "very good" (diff= 0.02, p=0.02) wherein the values were underestimated by both the proxy measures. Overall, the agreement between self and proxy HRQoL ratings was poor with Proxy 1 (CCC=0.20) as well as Proxy 2 (CCC=0.17) reports. Using Proxy 1, mothers had a significant agreement (CCC=0.28, 95% CI: 0.05, 0.49) which was also higher than with fathers. When reported independently, the self-proxy concordance from the proxy-proxy perspective across domains was the lowest for "feeling worried, sad or unhappy" (AC1=0.58) followed by "having pain or discomfort" (AC1=0.68), "doing usual activities" (AC1=0.69), "looking after myself" (AC1=0.78) and highest for "walking about" (AC1=0.88). In the second stage deliberation, seventeen children and eight parents changed their responses for one or more domains. The inter-rater agreement for the deliberation sub-sample increased for the HRQoL values from fair (0.23, 95% CI: -0.07, 0.49) to significant and moderate (0.50, 95% CI: 0.24, 0.7). An improvement in agreement was also observed post deliberation across all domains.

Conclusions: This study demonstrated that the dyad deliberation approach improved agreement in child-self and proxy HRQoL reports. Further research is needed to explore child-self and proxy assessment of HRQoL and the potential for the dyad deliberation approach to improve agreement in larger and more diverse community-based samples and paediatric patient populations.