Children's Hospital of Philadelphia PolicyLab

Patient-proxy Agreement on Health-related Quality of Life in Juvenile Fibromyalgia Syndrome

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Health-related quality of life (HRQoL) measures serve as important indicators of pain-related physical and psychosocial function in youth with juvenile fibromyalgia syndrome (JFMS). While the administration of parent-proxy reported HRQoL measures in the assessment of JFMS is common, its added clinical value to patient self-reports is unclear. We aimed to determine the level of agreement on HRQoL among patients with JFMS as well as their parent-proxies and to determine factors associated with this agreement. We performed a retrospective, cross-sectional cohort study of children aged 8 to 17 years diagnosed with JFMS and presenting for initial evaluation to a pediatric rheumatology pain clinic between April 2017 and May 2018. All patients and proxies were administered the Pediatric Quality of Life Short Form 15 Generic Core Scales (PedsQL SF-15) as part of routine clinical care. We calculated absolute discrepancy scores (absolute value of parent-proxy score minus patient score) to describe the extent of difference in HRQoL scores between parent-proxies and patients. We examined agreement between parent-proxy report and patient self-report via intraclass correlation coefficients (ICCs), stratified by age and sex, as well as Bland-Altman plots. We also used multivariate regression models to determine factors associated with level of agreement. A total of 65 patient-proxy pairs were included in this study. ICCs demonstrated good to excellent agreement between all parent-proxy and patient measures of HRQoL irrespective of the patient's age or sex. The level of agreement was not associated with pain duration or pain severity but less agreement on psychosocial HRQoL was associated with older patient age (? = 1.30; $p < 0.05$). This study in youth with JFMS demonstrated good to excellent patient-proxy agreement across all domains of the PedsQL SF-15 irrespective of patient's age or sex. Our findings suggest that parent-proxy reports do not provide additional information beyond that obtained from the patient self-report of HRQoL according to the PedsQL SF-15. In order to facilitate children and adolescents with JFMS becoming partners in their own healthcare, and to decrease the burden of multiple questionnaires, we propose focusing on patients' own perceptions of HRQoL in the clinical setting.

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