**Title**: Reevaluating Quality of Life Measurements for Nonverbal Autistic Children: Addressing Applicability and Impact

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**Introduction**: Autistic individuals report experiencing a lower quality of life (QoL) compared to non-autistic peers (Graham Holmes et al., 2020), and many autistic individuals prioritize research aimed at improving their QoL (Benevides et al., 2020; Gotham et al., 2015) (Gotham). Approximately 35% of autistic individuals have co-occurring intellectual disability (ID; Maenner et al., 2023); however, existing literature on QoL in autism has primarily focused on verbal individuals with average to above-average cognitive abilities. This study seeks to address this critical gap by evaluating the suitability of standard QoL measures for minimally verbal autistic individuals with ID. Parents/caregivers of minimally verbal autistic children with co-occurring intellectual disabilities responded to items on a standard QoL measure and provided qualitative feedback about their experience completing the surveys.

**Method**: 76 parents of autistic children ages 5-17 years completed the Patient-Reported Outcomes Measurement Information System (PROMIS) Autism Battery-Lifespan (PAB-L). All autistic children were reported to be minimally verbal (i.e., no more than phrase speech) and have a co-occurring intellectual disability. The PAB-L has demonstrated strong feasibility, acceptability, and reliability in a large sample of autistic individuals (Graham Holmes et al., 2020); however, most previous respondents reported on verbal children without ID. Based on initial interviews with parents of youth with co-occurring ID who had completed the PAB-L and found the questions difficult to answer, we added a “not applicable (N/A)” response option for each item and collected open-ended written feedback to further capture participant perspectives. We evaluated the proportion of parents who endorsed the item as N/A for their child. An independent coder utilized a content analysis approach for the qualitative responses.

**Results**: The variability in the proportion of individual items endorsed as N/A across domains ranged from 3.9% in the Sleep Disturbance domain to 42% in the Meaning & Purpose domain. The scales with the highest endorsements were Meaning & Purpose (33.9%), Peer Relationships (23.5%), and Psychological Stress (23%), whereas the lowest were observed in the domains of Sleep Disturbance (4.1%), Sleep Impairment (4.6%), and Parent Positive Affect (7%). The average proportion of items endorsed as N/A across all scales was 16.12%. In participants’ open-ended responses, we found themes of frustration, exclusion, and uncertainty. One parent stated: “But the survey also asks the parent to speculate on what their child is thinking and characterize their child's feelings about many issues that the child often cannot themselves articulate due to limited verbal abilities and cognitive limitations that make it difficult for a child to conceptualize their future, their goals or even their feelings”.

**Discussion:** The results suggest that certain domains of the PAB-L may not be suitable for measuring QoL among minimally verbal autistic children with co-occurring ID. Overall, 16.12% of items were endorsed as not applicable by parents of autistic children, who were minimally verbal with co-occurring ID. Specifically, parents identified that domains with abstract language and involved assumptions about a child's thoughts and emotions were less applicable than those assessing observable behaviors. By upholding caregiver perspectives on the relevance of QoL tools, we can deepen our understanding of the factors that influence the QoL among this population and make meaningful strides towards improving QoL for all autistic individuals.

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