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RESEARCH NETWORK
for Children and Youth with Special Health Care Needs and Their Families

Child Quality of Life: A Review of Existing Measures



To measure the impact of interventions on the health and well-being of children and youth with special healthcare needs (CYSHCN) and the important subset of children with medical complexity (CMC), quality of life (QoL) is an important construct to measure.

Previous work by the national CMC CoIIN found that topic areas in the literature did not resonate with a broad spectrum of families' priorities in optimizing QoL for their children. Systematic description of existing measures and identification of gaps where better measurement is needed can inform future work to improve QoL measures.

METHODS

- We conducted a scoping review of worldwide literature to identify 41 generic (i.e., non condition-specific) QoL measures, all surveys, that had been developed or validated in one or more populations of CYSHCN
- We sought to compare the content of all available measures, including related measures from "gray literature" and other sources such as the National Survey of Children's Health, to objective QoL criteria for CMC, to identify areas where current measurement is adequate and to identify gaps where measure adaptation and/or development is needed.
- Study team members compared ("mapped") the wording of questions among 35 available surveys to domains (groups) of a healthy life for children with medical complexity, and elements within those groups, that were developed by Elizabeth Barnert and colleagues at UCLA (Pediatrics, 2018) using input from multiple points of view including families.

IMPLICATIONS

- Recommending measures for use is somewhat difficult, as none are truly comprehensive or outstanding and their utility depends on the needs of end-users.
- Even so, some measures appear to be more comprehensive than others in their scope when compared to Barnert's 10 domains of a healthy life for CMC, and some rely less on specific functional abilities (e.g., walking) than others.
- These data will be contained in the searchable QoL measures database.

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MAJOR FINDINGS

The scoping review identified 305 studies, representing 41 distinct QoL surveys. Surveys were validated in a variety of CYSHCN populations and are available in multiple languages.

- The measure mapping work found that QoL surveys covered one or more elements from all 10 domains of a healthy life for CMC, but only the NSCH (8/10) and the Impact of Childhood Illness Scale (6/10) covered more than 5 domains.
- The Health Related QoL (HrQOL) domain was covered by all 35 surveys, but the Family-Centered Medical Home and Health Care System Supports domains were covered by just 2 each.
- Within the surveys, 40% of items did not map to any elements of a healthy life, and 36% of the 77 elements were not covered by any measure. Moreover, 73% of surveys rely on one or more physical functions as determinants of QoL, raising questions about their relevance to CMC.
- We concluded that despite many existing QoL surveys, only HrQoL is described widely, leaving many elements of a healthy life for CMC unmeasured, especially those related to health systems.
- Another major limitation is that none of the 35 surveys were validated for use with neurodiverse/cognitively diverse respondents. This leaves considerable work to be done to better measure how CMC experience a healthy life.

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PRODUCTS TO DATE

In addition to two papers being submitted to peer-reviewed journals and multiple abstracts presented at national meetings, we are developing a searchable measures database and recommendations for use of existing measures.

We also are developing plans to prioritize and conduct measure improvement and development based on our findings.

IMPACT

- The results of our measure mapping project provide quantitative evidence that agrees with the COIIN group's sense that the current state of child QoL measurement is inadequate.
- Though not a dedicated QoL survey itself, items on the NSCH that are related to QoL (n=38) touch on 8 of the 10 domains, more than any other measure. A combination of the NSCH and one of several other QoL surveys could cover at least some elements of all 10 domains. Other combinations of measures may cover more individual elements within the 10 domains as well.

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