

Title: Evidence of Nonverbal Self-reported Quality of Life in Medically Complex Children

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Practice problem: Quality of Life (QOL) assessment is a fundamental aspect of understanding patients/families' needs when confronting a serious or life-threatening condition. There is a lack of knowledge about how to assess children's long-term needs. Does the literature offer evidence for QOL assessment and do practicing pediatric nurses have the knowledge and skills to assess QOL in nonverbal medically complex children?

Purpose: This evidence-based practice (EBP) project describes current evidence for assessing QOL in nonverbal medically complex children, ages 5-18 years, living with a congenital disorder, childhood injury, or disease process affecting their ability to verbally express needs.

Methods: A search for evidence consisted of a literature review, guidelines, policies, quality improvement projects on medically complex children and the development of a needs assessment to serve as a primary evidence source. Forty-five pediatric nurses practicing in sub-acute care settings outside of an inpatient unit responded to ten questions via Survey Monkey in Spring 2019.

Findings/Results: Current evidence suggests continued reliance on parent/caregiver-proxy to assess QOL and a lack of consensus on best practice guidelines and QOL assessment tools. Majority (80%) of pediatric nurses queried stated it is extremely important to assess QOL in children unable to speak. Consistent with literature, pediatric nurses reported reliance on parent report and physical condition assessment (86%) and provider assessment (73%). Least reported methods were validated pediatric assessment or computer-based animated/adaptive tools (11%). Existing literature and nurse respondents identified barriers to appropriately assessing QOL from the child's own experiences: lack of clinical documentation, validated QOL measures, and education, and discomfort communicating with nonverbal children. Evidence dissemination through presentation utilizing the Translating Research into Practice sheet is ongoing.

Implications: There is a need for additional education and the development of QOL instruments to assist providers and families to understand children's needs when words are not available.