



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



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Statement of the Problem

- Quality of Life (QOL) assessment is a fundamental aspect of understanding patients/families' needs when confronting a serious or life-threatening condition.
- 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 their own needs.

Background/Literature Review

- Current evidence suggests reliance on parent or caregiver-proxy and a lack of consensus on best practice guidelines and QOL assessment tools.

Barriers/Limitations

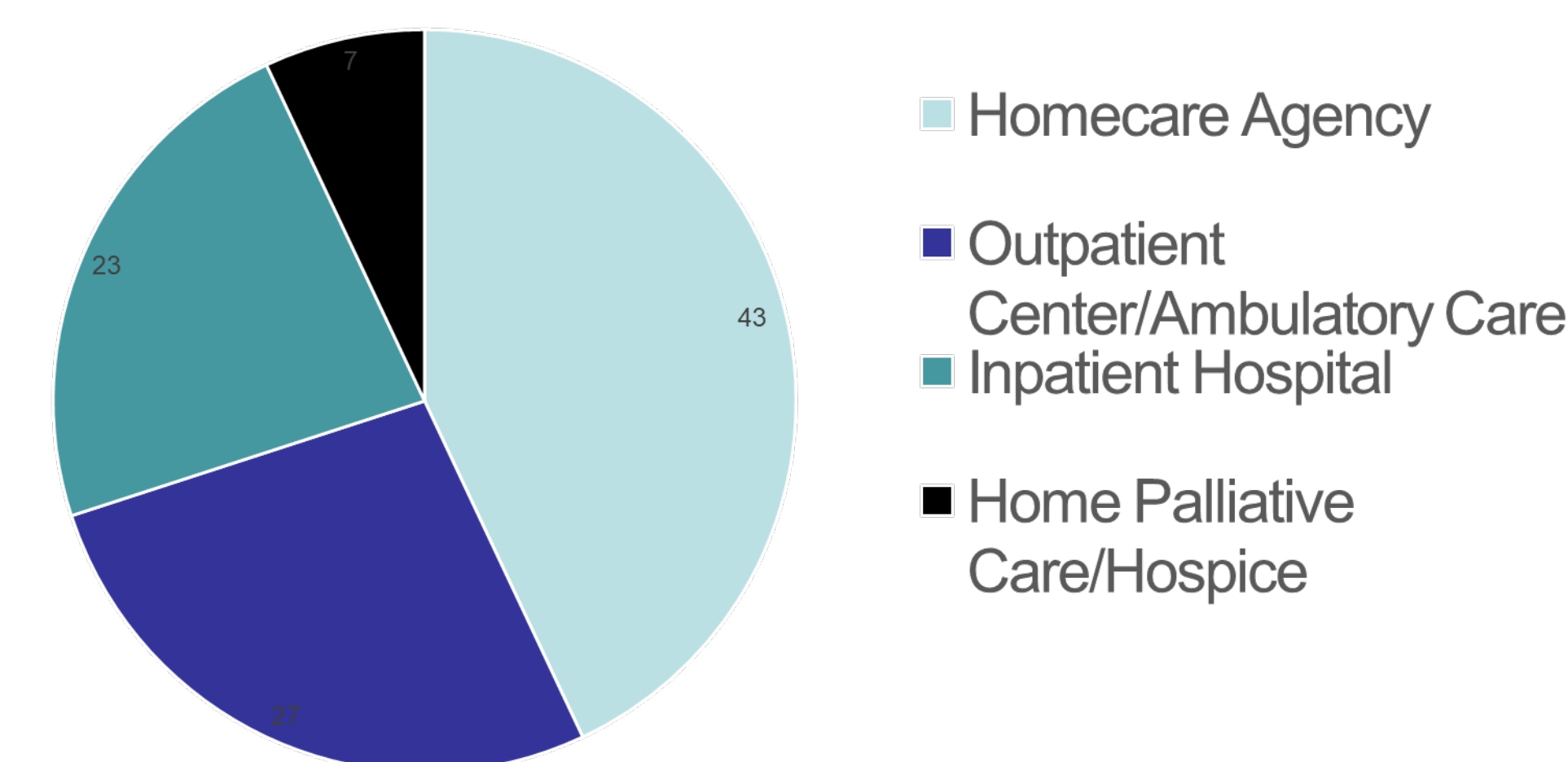
Existing literature and nurse respondents identified barriers and limitations in appropriately assessing QOL from the child's own experience:

- lack of clinical documentation
- lack of validated pediatric QOL assessment tools
- lack of nursing education
- discomfort communicating with nonverbal children

Methods

- Search for evidence reviewed literature, guidelines, policies, and quality improvement projects related to medically complex children
- A nursing needs assessment was developed to serve as a primary source of evidence and was completed by 45 pediatric nurses in Spring 2019

Nurses Primary Practice Location

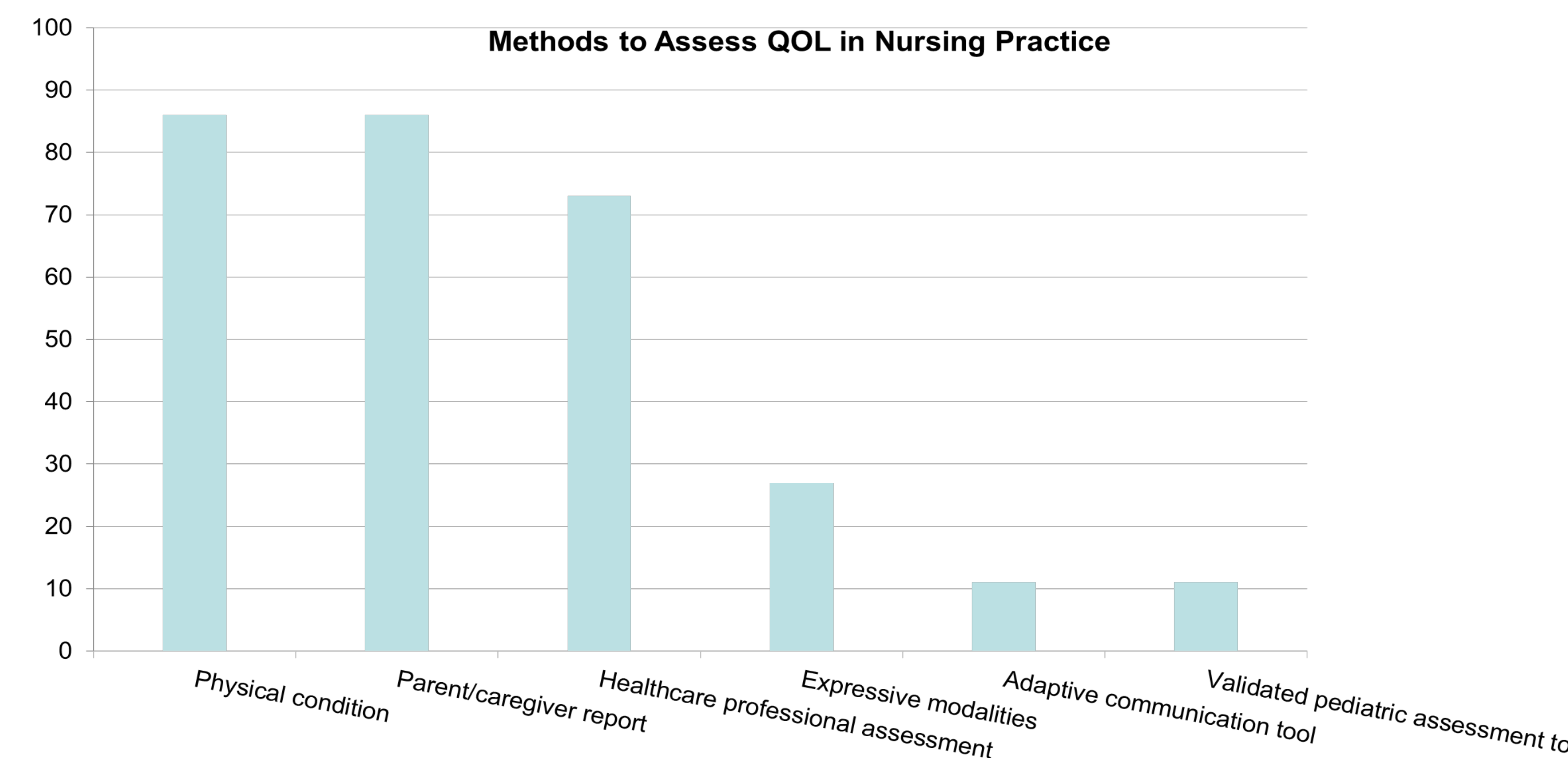


Nursing Experience

Mean: 9 years
Most: 36 years
Least: 1 year

Findings

- Most (80%) pediatric nurses stated it is extremely important to assess QOL in children unable to speak.
- Consistent with literature, pediatric nurses rely on parent report, physical condition assessment, displaying expressions/emotions, or provider assessment of QOL.
- Although nurses (89%) reported they have NOT received formal education on how to assess QOL, almost half (44%) are asked to assess QOL at least once a week.



Implications

Additional education and development of appropriate QOL instruments are needed to assist healthcare professionals and families in understanding children's own needs when words are not available.

Dissemination

Translating Research Into Practice (TRIP)

Nonverbal Self-reported Quality of Life in Medically Complex Children

What Does the Evidence Say?

"Quality of Life (QOL)" is a term used when patients, families, and healthcare professionals are trying to understand the impact of serious illness. There are two key concepts associated with QOL: 1) It is multi-dimensional and includes physical, social, psychological, and spiritual dimensions, and 2) it can only be determined by the person (<https://getpalliativecare.org/quality-of-life>).

Although family members, nurses, physicians, and other health professionals can make significant observations, research consistently shows important differences between how patients, and those around them, interpret the question: How is your quality of life? In children who cannot self-report it is difficult to understand QOL dimensions from their own perspective (Lim, Velozo, & Bendixen, 2014; Jones & Weisenfluh, 2003).

There is still a lack of consensus on best practice guidelines and QOL assessment tools. Current recommendations remain relying on parent or caregiver report in response to questions in an individualized care plan or goals of care conversation (Marino et al., 2011; Hinds, Menard, & Jacobs, 2012).

Change in Practice?

Pediatric nurses have information available to them, beyond parent report, to assess a nonverbal child's QOL:

- Assess physical condition (e.g. pain, functional status, and unrelieved symptoms) (Cheng et al., 2018)
- Coordination of care with Expressive Therapists (e.g., Play Therapy, Creative and Expressive Arts Therapy, Movement/Dance, PT, OT, Speech, or Massage) (Ekberg, Bradford, Herbert, Danby, & Yates, 2015)
- Communication directly with the child using and adaptive/augmentative communication device (Markham, Van Laar, & Dean, 2011; Montgomery, Savin, & Hendricks-Ferguson, 2017)
- Assessment of emotions (displaying expressions of fear/anxiety, lack of control, etc.) (Mentzer, Beas, Chang, Reed, & Gold, 2013)
- Intake of sociocultural stressors (distress about siblings/parents, isolation, socioeconomic effects on well-being, specific cultural/ethnic practices of the family)

Validated Assessment Tools

- The PedsQL™ (Pediatric Quality of Life Inventory™), with specialty pediatric assessments for:
 - ✓ Gastroenterology
 - ✓ Cardiology
 - ✓ Oncology
 - ✓ Neurology
 To Access Visit: <https://www.pedsqol.org/>
- KIDSCREEN Questionnaire
To Access Visit: <https://www.kidscreen.org>

References:

Ekberg, S., Bradford, N., Herbert, A., Danby, S., & Yates, P. (2015). Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: a qualitative systematic review protocol. *BMJ Open*, 9(1), e005293. doi:10.1136/bmjopen-2015-024153

Cheng, L., Wang, L., He, M., Feng, S., Zhu, Y., & Rodgers, C. (2018). Perspectives of children, family caregivers, and health professionals about pediatric oncology symptoms: a systematic review. *Support Care Cancer*, 26(9), 2957-2971. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6271444/>

Hinds, P. S., Menard, J. C., & Jacobs, S. S. (2012). The child's voice in pediatric palliative and end-of-life care. *Progress in Palliative Care*, 20(6), 337-342. doi:10.1179/1743291X12Y0000000035

Jones, B., & Weisenfluh, S. (2003). Pediatric palliative and end-of-life care: Developmental and spiritual issues of dying children. *Smith College Studies in Social Work*, 73(3), 423-443. doi:10.1080/00377130309517695

Lim, Y., Velozo, C., & Bendixen, R. (2014). The level of agreement between child self-reports and parent proxy-reports of health-related quality of life in boys with Duchenne muscular dystrophy. *Quality of Life Research*, 23(7), 1945-1952. doi:10.1007/s11136-014-0642-7

Marino, B., Drotar, D., Cassidy, A., Davis, R., Tomlinson, R., Mellion, K., . . . Ittenbach, R. (2011). External validity of the pediatric cardiac quality of life inventory. *Quality of Life Research*, 20(2), 205-214. doi:10.1007/s11136-010-9731-4

Markham, C., Van Laar, D., & Dean, T. (2011). Development of a quality of life measure for children and young people with speech, language, and communication needs. *Evidence-Based Communication Assessment and Intervention*, 5(4), 265-275. doi:10.1080/17465939.2012.684342

Mentzer, J., Beas, V., Chang, J., Reed, K., & Gold, J. (2013). Mood and Health-Related Quality of Life Among Pediatric Patients With Heart Failure. *Pediatric Cardiology*, 34(2), 431-437. doi:10.1007/s00246-012-0477-3

Montgomery, E. K., Savin, J. K., & Hendricks-Ferguson, J. V. (2017). Communication During Palliative Care and End of Life: Perceptions of Experienced Pediatric Oncology Nurses. *Cancer Nursing*, 40(2), E47-E57. doi:10.1097/NCC.0000000000000363

Acknowledgements/References

Mentor: Nancy English, PhD, APRN, CHPN

References:

Boland, L., Graham, I. D., Légaré, F., Lewis, K., Jull, J., Shephard, A., . . . Stacey, D. (2019). Barriers and facilitators of pediatric shared decision-making: a systematic review. *Implementation Science*, 14(1). doi:10.1186/s13012-018-0851-5

Hinds, P. S., Menard, J. C., & Jacobs, S. S. (2012). The child's voice in pediatric palliative and end-of-life care. *Progress in Palliative Care*, 20(6), 337-342. doi:10.1179/1743291X12Y0000000035

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References:

- Ekberg, S., Bradford, N., Herbert, A., Danby, S., & Yates, P. (2015). Healthcare users' experiences of communicating with healthcare professionals about children who have life-limiting conditions: a qualitative systematic review protocol. *JBIR Database of Systematic Reviews & Implementation Reports*, 13(11), 33-42. doi:10.11124/jbisrir-2015-2413
- Cheng, L., Wang, L., He, M., Feng, S., Zhu, Y., & Rodgers, C. (2018). Perspectives of children, family caregivers, and health professionals about pediatric oncology symptoms: a systematic review. *Support Care Cancer*, 26(9), 2957-2971. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/29774474>
<https://link.springer.com/article/10.1007%2Fs00520-018-4257-3>. doi:10.1007/s00520-018-4257-3
- Hinds, P. S., Menard, J. C., & Jacobs, S. S. (2012). The child's voice in pediatric palliative and end-of-life care. *Progress in Palliative Care*, 20(6), 337-342. doi:10.1179/1743291X12Y.0000000035
- Jones, B., & Weisenfluh, S. (2003). Pediatric palliative and end-of-life care: Developmental and spiritual issues of dying children. *Smith College Studies in Social Work*, 73(3), 423-443. doi:10.1080/00377310309517695
- Lim, Y., Velozo, C., & Bendixen, R. (2014). The level of agreement between child self-reports and parent proxy-reports of health-related quality of life in boys with Duchenne muscular dystrophy. *Quality of Life Research*, 23(7), 1945-1952. doi:10.1007/s11136-014-0642-7
- Marino, B., Drotar, D., Cassedy, A., Davis, R., Tomlinson, R., Mellion, K., . . . Ittenbach, R. (2011). External validity of the pediatric cardiac quality of life inventory. *Quality of Life Research*, 20(2), 205-214. doi:10.1007/s11136-010-9731-4
- Markham, C., Van Laar, D., & Dean, T. (2011). Development of a quality of life measure for children and young people with speech, language, and communication needs. *Evidence-Based Communication Assessment and Intervention*, 5(4), 216-225. doi:10.1080/17489539.2012.688342
- Menteer, J., Beas, V., Chang, J., Reed, K., & Gold, J. (2013). Mood and Health-Related Quality of Life Among Pediatric Patients With Heart Failure. *Pediatric Cardiology*, 34(2), 431-437. doi:10.1007/s00246-012-0477-3
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