

**Trends in Pediatric Palliative Care Research (TPPCR) 2024; Issue #1: Commentary on *Toro-Perez et al.***

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**Abstract:**

This TPPCR commentary discusses the 2023 paper by Toro-Perez et al., “Evaluating quality of life in pediatric palliative care: a cross-sectional analysis of children's and parents' perspectives” published in European Journal of Pediatrics.

*This commentary is a part of the Trends in Pediatric Palliative Care Research commentary series. To learn more or to sign up for our monthly newsletter visit: <https://pediatricpalliative.com/research-blog/>*

Definitions of pediatric palliative care typically include something about an overall goal being to improve quality of life (QOL) for both the child and family.<sup>1,2</sup> Some programs have even incorporated QOL into the names of their programs (e.g., Quality of Life for All [QOLA] or Quality of Life and Advanced Care [QoLA Care]). If improved QOL is the goal, how do we know we have achieved it? There are numerous tools available to measure QOL in children, however, very few, if any, have been developed from inception with direct incorporation of the perspective of children with life-threatening conditions or tested for reliability and validity in this population.<sup>3</sup> The diversity of ages, developmental needs, diagnoses, and cognitive and physical abilities in the population of children who might benefit from palliative care makes it a challenge to identify items that could be incorporated into a tool to measure QOL that would be applicable to all. Thus, I was struck by one of the articles in this month's citation list where a 0-10 scale was used to assess QOL.

Toro-Perez and colleagues aimed to compare perceptions of the child's QOL between children (age 9 years or more) living with a life-threatening condition and their parent. They recruited 44 parent-child dyads and adapted the Distress Thermometer to ask the child and parent "In general, how do you rate your quality of life (well-being) at the present time? The study findings indicated that parents tended to rate the child's QOL lower than the children did themselves. This finding is similar to other research which has shown discrepant parent and child assessment of a variety of symptoms, with less "visible" psychological symptoms such as worry or sadness being seen as worse by parents than by children themselves.<sup>4,5</sup> Discrepant scores highlights the importance of incorporating the child's perspective whenever possible in assessing their experience, particularly for something as multifaceted and invisible as QOL.

My interest in the article, however, centred more on the use of the 0-10 scale for assessing QOL. These types of scales are commonly used as screening tools for pain and a variety of other symptoms. Assessment does not stop with choosing the number on the scale. If a child were to say their pain was an 8/10, the assessment would continue with further questions – often following mnemonic such as OPQRST to assess onset, precipitating/palliative factors, quality etc. Treatment decisions are made based on the responses to all the questions rather than simply on the score between 0 and 10. However, evaluation of the impact of the treatments, circles back to the score and whether there has been a reduction in the score to a level that is more tolerable for the child. In research, the score can be used as an outcome measure when testing interventions. Similar to pain assessment, I wondered about creation of a mnemonic to guide follow-up questions for further assessment of QOL. While palliative care clinicians are experts at asking questions, uncovering goals of care, and determining what is most important to children and families, a guide to direct specific areas for assessment in relation to QOL would ensure comprehensive assessment. Given the demonstrated discrepancy in assessment scores between parents and children, development of that guide needs to start with the voices of children living with life-threatening conditions to ensure it is comprehensive and relevant to their experience and priorities. For children unable to speak for themselves for whatever reason, parent report is still critically important. Ultimately, providing high quality and impactful palliative care is about improving QOL scores regardless of what the starting score is or who is providing the rating.

## References

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