Trends in Pediatric Palliative Care Research (TPPCR) 2021; Issue #8: Commentary on *Barks et al.*

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Abstract:

This TPPCR commentary discusses the 2021 paper by Barks et al, "Assessment of parent understanding in conferences for critically ill neonates." published in Patient Education and Counseling.

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"They just don't get it."

Ask any healthcare provider who works in a neonatal intensive care unit (NICU), and they'll be able to recall a time they have heard a similar comment regarding a family's understanding of their child's condition. This study identifies the reason- the family "doesn't get it" because the care team didn't effectively assess their understanding.

Barks et. al¹ evaluated 50 family meetings from 24 cases of infants in the NICU with neurological conditions for detailed assessments of parent understanding. Assessments of parent understanding were coded as 1) partial assessments, 2) close-ended assessments, and 3) open assessments. The fourth category would have been a teach-back, but no teach-backs were identified in any of the 50 meetings.

Short phrases such as "*okay?*", "*alright?*", and "*you know?*" were characterized as partial assessments. Partial assessments comprised 56% of the assessments of parent understanding identified in the study. The study suggested that clinicians sometimes used partial assessments to seek permission to move on to a new topic. Close-ended statements included statements like "*was that clear?*", or "*any questions so far?*". 28% of assessments identified were characterized as close-ended. Open-ended assessments represented 16% of assessments of understanding, making them the least common type identified in this study. These assessments typically involved a member of the healthcare team explicitly asking parents to ask questions after presenting new medical information (Barks et. al, 2021). Open-ended assessments tended to prompt a more comprehensive response and further questions from parents.

Interestingly, half of all assessments did not yield any verbal response from parents and family members. Regardless of assessment type, parents only asked clarifying questions about 25% of the time. Considering the difficulty and complexity of situations that lead to these types of meetings, it is unlikely that parents genuinely have no questions 75% of the time. Future work could explore whether or not clinicians perceive that parents truly have an excellent understanding of medical information when they claim to have no questions.

Future research could evaluate what factors empower parents to ask more questions in family meetings and use these findings to create a comprehensive framework or guide to having more successful family meetings. Using a guide is an effective intervention for complex communication like the meetings evaluated in this study. The Serious Illness Conversation Guide (SICG) is one widely implemented example of this (Ariadne Labs, 2021). When the SICG was adapted for pediatrics, clinicians commented that it was not more time-consuming than standard practice, and the use of a guide allowed for a sensitive and thorough conversation (van Breemen, 2018²).

The family meeting is one of the most essential clinical interventions that take place in a NICU, and the complexity of these meetings cannot be understated. Evaluating assessments of understanding in family meetings is a critical first step to understanding the complex interactions in these meetings.

The balance of compassion, information-sharing, and assessment of understanding required for an effective meeting is extraordinarily difficult to achieve. This study takes an essential step towards understanding the family meeting and developing evidence-based guidelines towards supporting families through these meetings.

References

1. Barks, M. C., Schindler, E. A., Ubel, P. A., Jiao, M. G., Pollak, K. I., Huffstetler, H. E., & Lemmon, M. E. (2021). Assessment of parent understanding in conferences for critically ill neonates. *Patient Education and Counseling*. <https://doi.org/10.1016/j.pec.2021.06.013>
2. van Breemen, C. (2018). Adapting the Serious Illness Conversations Guide for use in pediatrics. *Journal of Palliative Medicine*, 21(12):1683. <https://doi.org/10.1089/jpm.2018.0515>