Trends in Pediatric Palliative Care Research (TPPCR) 2024; Issue #2: Commentary on *Vemuri et al.*

Dr. Kate Nelson, MD, PhD

The Hospital for Sick Children, Toronto, Canada, Staff Physician, Paediatric Advance Care Team

Email: kate.nelson@sickkids.ca

Abstract:

This TPPCR commentary discusses the 2023 paper by Vemuri et al., "Shepherding parents to prepare for end-of-life decision-making: a critical phenomenological study of the communication approach of paediatricians caring for children with life-limiting conditions in Australia" published in BMJ Open.

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In the interesting collection of articles this month, one particularly caught my eye: Sidharth Vemuri and colleagues' study, "Shepherding parents to prepare for end-of-life decision-making: a critical phenomenological study of the communication approach of paediatricians caring for children with life-limiting conditions in Australia." The team tackled a particularly challenging question—how to study the meaningful conversations about goals of care that occur long before decisions are made, the conversations that are the heart of the work we do in pediatric palliative care. They came to a creative solution: a qualitative study based on medical simulation.

The research team worked with bereaved parents and "medically trained actors" to develop two scenarios about a child with "life-limiting neurodisability" during which a discussion of advanced care planning would feel natural but not compulsory. (Scenario 1: first intensive care unit admission for non-invasive ventilation; Scenario 2: the first clinic visit after discharge from that admission). The two actors then led simulations with participants (11 general pediatricians, 7 intensivists) matched to their practice type. The research team observed the simulation, then separately interviewed the clinicians and actors. They used critical phenomenology with thematic analysis performed by the study team, which included two palliative care pediatricians, one bereaved parent/advanced practice nurse, and one clinical ethicist. In phenomological studies, researchers try to understand how a group of participants with a shared identity make sense of an experience.[1] The study authors explained that they chose this design for reasons conceptual (because end-of-life conversations are particularly culture-bound) and pragmatic (so that they could include both first-person interviews and the third-person simulation observations as study data).

The researchers identified 3 themes in the clinicians' approaches to these conversations. First, clinicians were deliberate in laying groundwork for future difficult decisions by using open-ended questions to help parents think about quality of life/suffering and to reflect about risks/benefits of therapies. Second, clinicians were intentional about the "pace" of these conversations—gently pushing at the tender spots if the conversation was shallow or steering away/responding vaguely if they judged questions premature. Third, clinicians "recogni[zed] the need for courage to face risk" in the choice to explicitly address end-of-life decision making, as the conversation could damage the therapeutic relationship. The researchers named this process of laying groundwork for future difficult decisions while maintaining the relationship, "shepherding."

I found this article intriguing for two reasons. First, I was impressed by the richness of the data they acquired through a medical simulation. These types of conversations require finesse from the clinician, gauging the openness of the parents to engagement, which makes them unpredictable and essentially impossible to study prospectively—unless, like the researchers, you can find a strategy to ensure that a meaningful conversation will occur. Their approach is novel—the researchers wrote several companion pieces about the process of developing the scenarios and their rationale for the use of simulation as a source of qualitative data. Given how challenging palliative care communication is to study, I thought it was important to highlight this approach as a potential new tool in our research toolbox.

Most importantly, though, the construct of "shepherding" resonated strongly for me as a pediatric palliative care staff physician. These early conversations are the ones where I feel most vulnerable, recognizing that a misstep might damage the therapeutic alliance. It is a conversational dance where I intuitively titrate tone, bluntness, and humor to match the situation as best I can. Learning how to do this

dance effectively is a major developmental task of pediatric palliative care fellowship—and it is hard to teach. As an experienced clinician, I still frequently make missteps, some with lasting repercussions for the relationship. Ceding a high-risk conversation to a learner—particularly one that is non-urgent—is hard, and when I do, I struggle to stay quiet. I agree with the authors that having specific language to describe the construct is the first step to being able to research and teach it. Though I think "shepherding" is not an ideal term, the construct itself is well-articulated. I hope this study is the first of many exploring this essential skill.

References

1. Laverty, S.M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International journal of qualitative methods*, *2*(3), 21-35.

2. Salamon, G. (2018). What's critical about critical phenomenology?. *Journal of Critical Phenomenology*, *1*(1), 8-17.