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## ***Parent Perspective and Response to Challenges and Priorities for Pediatric Palliative Care Research***



To the Editor:

We write to express our appreciation for the many tributaries of care and concern around pediatric palliative care research that are reflected in the article **Challenges and Priorities for Pediatric Palliative Care Research** (Feudtner et al.<sup>1</sup>). We are caregivers whose children and families have been the beneficiaries of pediatric palliative care, and we are dedicated to building awareness of its critical value in our roles as staff and parent members of the Courageous Parents Network, a national nonprofit organization whose mission it is to empower, orient, and support parents caring for children with serious illness. We are greatly encouraged by the breadth of issues and depth of understanding evidenced in this article. We are delighted that these distinguished investigators are expressing interest and enthusiasm for pursuing collaboration and direction of resource, and we envision endless benefit.

While there are times and places for many different voices, our group noted that the panel participating in this study was lacking *our* voices. The involved providers clearly have deep expertise and know our population well. We believe, however,

that there is no real substitute or proxy for actual family experience.

Going a step further, we can state with confidence that where our providers have encouraged our input and relied on our knowledge of our children, all parties have found greater satisfaction with the care process—no matter how sad the ultimate outcome is. *Families can bring this knowledge and experience to the research agenda.* Families could be a part of the research design, not just as subjects but also as investigators. The work of the Patient-Centered Outcomes Research Institute is a good model for this.

In the meantime, how can what matters for the advancement of the field and the academic advancement of the individual researchers be effectively married with what matters to families?

In the spirit of mutual understanding, we brainstormed needs and desires and offer this prioritization from the list in the article.

1. Communication and facilitating goals-of-care clarification and decision-making: In our experience, pediatric palliative care providers own this space—it is the unique domain of pediatric palliative care. Other specialists may or may not be trained to pursue the family's goals of care or to have the long view of the patient's and family's priorities. And yet, having the ability to at least initiate important conversations on these topics is critical to the family's well-being. We suggest—no, hope—that investigation and publication of best practices would travel upstream, that is, to equip providers in all related fields, and at all levels, with tools to support safe and candid communication.
2. Improve symptom management and quality-of-life interventions: While we designated this as our second priority, symptom management and related interventions are, in fact, inextricably linked to goals of care (previous point) and family impact (the next point). A child's pain, for example, affects the entire family. When the child suffers, the parents' ability to think clearly and rationally, to communicate with each other and with the care team, and even to care for other children in the family can all be severely compromised. Ideally, the burden of symptom management would be left to other specialists. However, the fact is that palliative care specialists take into account the whole child in ways that specialists may miss. Anything and everything that improves this practice is relevant to the most important role of pediatric palliative care: stewardship of the child and family's quality of

life—particularly as it relates to mitigation of stress and distress.

3. Understand family impact and facilitate or improve family adaptation and coping: The authors acknowledge that the research is woefully insufficient to guide design of these practices, yet they are of paramount importance. Actually, this data would be comparatively easy to collect and analyze, especially as families are eager to contribute to the body of knowledge about the lived experience. Many see this as a part of their responsibility to their lost child's memory and find that participating in activities that honor their child is actively therapeutic.

There is no question that as practitioners and families work together on these and future priorities and goals and as the American Academy of Hospice and Palliative Medicine continues to highlight this work, we will ultimately see better and more patient-centered care all around.

Signed.

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