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# Surprised by Benefit in Pediatric Palliative Care Research

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The field of pediatric palliative care relies on studied outcomes to foster the foundational knowledge needed to guide best practice and inform interventions.<sup>1</sup> Research allows us opportunities to build or refine knowledge on which to improve current practice.<sup>2</sup> Research may not offer direct benefit to the participant but to future like others. For seriously ill children and their families, clinicians are seeking situations of benefit while protecting against harm. As the benefits and risks for children and families participating in palliative care research are largely unknown, most clinicians and review boards focus on the potential for harm. Institutional review boards may be reluctant to approve research for vulnerable populations using a biomedical model to assess harm without equally examining the perceived benefit of social and behavioral research findings.<sup>3</sup> We have witnessed this well-intended focus on hypothetical harm become a fear of potential harm, which translates into a resistance to approve pediatric palliative care research. This fear-harm cycle impedes research progress in this understudied population.

Although steps are put in place to ensure safety and protection, pediatric palliative care researchers do not currently have a guiding standard to measure burden, minimize harm, or trigger harm-recovery interventions. While consistently preparing to avoid harm, pediatric palliative care researchers have borne witness to profound benefits in conducting research with pediatric palliative care patients-including research that relies on hearing the child's voice at the end of life.<sup>4</sup> Benefits range from transparency to transcendence, an opportunity to engage in honesty and to be heard, memory making to legacy building, and symptom management to supportive interventions.

Our Pediatric Palliative Care Special Interest Group, while preparing to develop standards to assess harm and benefit, has documented researcher quotes regarding the witnessed benefits to children, families, and even clinicians of participating in palliative care research:

\* Benefit to clinician

"The initial [clinician] reaction in both study proposals [pediatric palliative studies] was apprehension and desire to protect their patients from something they thought might cause harm to patients and families and damage hope and faith in the medical team. However, after exposure to both palliative care and palliative care research, the reactions turned much more favorable, and my colleagues moved from apprehension about harm to embracing the benefits of each."

\* Benefit to family

"In the advanced planning study, I remember 1 parent thanking me for referring her and her son for the research study."

"The responses of the participants to their involvement are generally so positive it points to how much patients and families are waiting to have these difficult conversations and how relieved they seem to be that someone wants to ask these questions and listen to the answers. In fact, it seems that patients and families seem somewhat relieved."

"One parent said [at completion of an end of life study]: 'Of all the science-y things they ask me to do, this study was my favorite.'"

"After completing advance care planning for their grandson living with HIV [human immunodeficiency virus], the grandmother said to the grandfather, 'now that we know how to do this, we should do this for ourselves.'"

\* Benefit to patient

"One adolescent shared, 'there's certain things that[horizontal ellipsis] you want to talk about with people and you can't talk about it with them-because you don't know if they want to talk about it. But if someone is asking you those certain questions about those certain feelings, you know they can handle talking to you about it so[horizontal ellipsis] I felt a little better, a little, you know, relieved or relaxed after talking about it.'"

"Another adolescent with advanced cancer commented after his interview, 'The way you asked the questions was excellent. It was not too much pressure, and if it was, it would go in the box. So I think it was a really good method to know how kids are feeling, and they can get things off their chest, you know.'"

Pediatric palliative care study teams plan multiple ways to ensure their study does not cause harm, through their methods and through study-specific training. Some pediatric palliative care researchers are also expert clinicians, trained in human behavior to recognize emotional, verbal, and nonverbal cues that signify distress.<sup>5</sup> Their reflections provide insight that some bereaved parents want to tell their story to someone who will listen. Likewise, another parent may need a timely referral to psychosocial or behavioral services that might not have been otherwise rendered if the parent was not part of the study.

Study teams must and do report harm to review boards and implement an action plan to mitigate harm, but a higher standard would call for study teams to also report benefits. The latter are not currently collected in most palliative care studies, nor are most study teams trained to assess for benefit. Knowing the impact of research participation on participants-both harms and benefits-is a best practice that can lead to adapting research procedures.<sup>6</sup> Thoughtful research teams ask children and families directly about both harms and benefits as part of good science.<sup>7,8</sup> The current gap in knowledge on the risks and benefits to pediatric palliative care patients, their families, and their

clinicians means that there is not enough documented evidence to have yet developed a research guideline. Such a guideline could advance the science in a way that carefully and systematically protects pediatric palliative care participants and teams while promoting benefit. Scales and tools that have been initiated to explore benefit and burden could now advance the science into best practice research approach.<sup>9,10</sup>

In describing his childhood after his mother's premature death, literary scholar C. S. Lewis conveyed how his sadness of loss capped his goals at security and settledness (avoid harm) rather than joy or happiness (seek benefit).<sup>11</sup> His book, *Surprised by Joy*, attests that the joy he had long avoided seeking was later discovered "in the least likely place within the least likely circumstances" in a way that surpassed his expectations. Similarly, researchers investigating pediatric palliative care topics who commit to principled science, a high standard of patient protection, and ethical principles who currently limit their hopes to "avoiding harm" may be surprised by the benefits of their work to children, to families, and even to the care team.

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