

Paediatric Palliative Care Research *Has* Come of Age

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When we were invited to edit a special issue of Palliative Medicine dedicated to paediatric palliative care research, we realized that bringing us together mirrors the spectrum of research in the field. Dr. Bluebond-Langner examines seriously ill children, their families, their healthcare providers and systems of care through an anthropological lens. Dr. Wolfe tests hypotheses from data collected in seriously ill children, their families, their healthcare providers and systems of care. In working together to develop this special issue we hope to model the strength of blending qualitative and quantitative approaches to investigation, through which we can learn deeply about paediatric palliative care and generalize more broadly to disseminate our findings.

When we published the call for submissions, we asked the question, “Has paediatric palliative care research come of age?” We got our answer, the response to the call was truly astonishing. In total, we received 80 submissions of very high caliber. The review process was rigorous and lengthy. We used standard criteria for article acceptance including consideration of the rigor of study design, and aimed for diversity in methodology, topics, study subjects and region. We now offer the first ever major palliative care journal issue dedicated to paediatric palliative care research.

We would like to thank the screening reviewers from Palliative Medicine as well as external reviewers, no fewer than two per article - for their dedication to quality peer review. Catherine Walshe, editor in Chief and Debbie Asbury, Managing Editor of Palliative Medicine took extra care to make sure this was the highest caliber issue. We are most grateful to the authors for their patience and significant contributions.

What have we learned? Feudtner et al recently published the results of a workshop focused on establishing paediatric palliative care research priorities in the United States and similar practice settings. Full disclosure, we both participated in the workshop. In response, a group of parents of seriously ill children published a letter identifying their top three research priorities. We present the articles published in this issue as they align with these stakeholder priorities.

1. **Improve communication, elicitation of goals of care and decision-making:** A primary intervention in palliative care is establishing goals through high quality communication, a procedure grounded in specific skills. Re-goaling and further decision-making are also critical skills as serious illness evolves. In this issue, several studies further our understanding of these complex interventions. Janvier et al identify clinician communication behaviours that foster trust in parents of children with Trisomy 13 and 18. Cousino and colleagues report from a study of adolescents and young adults listed for heart transplant that while they actively participated in the decision to pursue transplant, they also wanted further discussion about their end-of-life options and preferences. In a study of adolescents and young adults undergoing bone marrow transplant Needle et al shows that adolescents and young adults are capable of meaningful deliberation in making this and future treatment decisions. The results of these and other descriptive studies are important in the development of effective interventions.

Two studies in this issue report on the early stages of communication interventions. Ekberg et al rigorously developed a discussion prompt list to support families in their communication about paediatric palliative care needs. Hein and colleagues identify key elements for advance care planning discussions as a step toward an intervention. Next steps include further translation of findings into rigorously tested communication interventions and dissemination.

2. **Advance symptom measurement (and other exposure and outcomes measurement) and improve symptom management and quality of life interventions:** A principle goal of palliative care is easing suffering and improving wellbeing in the seriously ill and their loved ones; a goal shared by parents. Investigators also note the need to delineate how to measure symptom and quality of life outcomes to effectively evaluate targeted interventions. Children with severe neurological impairment and their families have substantial palliative care needs and yet are the subject of very little research. In this issue, Reuther et al make a notable contribution by identifying six core domains of paediatric palliative care for these families including symptom control, as commonly seen in other populations.

Namisango and colleagues report on critical outcomes for children living with serious illness in several African countries. Lau and colleagues show that an intervention aimed at enhancing resilience outcomes in adolescents and young adults with cancer has less impact in more

disadvantaged populations. Schmidt et al describes the unintended consequences of trying to enhance quality of life in children receiving inpatient paediatric palliative care through a novel approach to hygiene. Collectively these studies demonstrate that we are only beginning to chip away at this domain of paediatric palliative care research.

3. **Understand family impact and facilitate or improve family adaptation and coping:** The family impact is a clear priority of paediatric palliative care and is exemplified by several studies in this issue. Thomas et al show that parents caring for seriously ill children receiving palliative care have substantial unmet needs. Lichtenthal and colleagues describe long-term regret and a sense of unfinished business in bereaved parents of children with cancer and impact on their bereavement outcomes. As a first step toward intervention development, Fuhrer and colleagues describe the feasibility of using network mapping to help parents identify sources of support. These studies show that along with our research in child wellbeing we also need to focus on family wellbeing.

4. **Analyse and improve systems of care, policy and education:** The delivery of paediatric palliative care invariably depends on its context and clinician actors. Using a realist review approach, Mitchell et al identify that paediatric palliative care is a multifactorial intervention and they call for a better understanding this complex service. Kaye et al identify unmet educational needs among nurses when caring for children in homebased hospice. Palliative transport is a means for returning children to their homes at end of life and Grosseohme and colleagues describe its feasibility and need for clinician preparedness and education. Dombrecht et al show that neonatal physicians and nurses receive insufficient support from their departments when it comes to the impact of confronted end-of-life decisions on their wellbeing. Paediatric palliative care delivery, whether by generalists or subspecialists, can only improve when systems of care, policy and education are aligned in the common goal of high-quality care of seriously ill children and their families.

There are many types of studies and voices that have not been captured in this issue, perhaps in part reflecting the ongoing challenges facing paediatric palliative care investigators. Among these challenges are those identified by Feudtner et al, including: diverse and small patient population size, complex relationships between all actors, few rigorously identified outcomes and measurement, limited well trained investigators with sufficient infrastructure and resources to conduct high quality research, a

presumed burden of paediatric palliative care research upon participants. Interestingly, in this issue Butler et al show that ethics committees do not scrutinize studies of children with life-limiting conditions differently than other studies and that other issues common to all research proposals, not subject matter, may be what is at issue. Other issues that have limited the scope of this special issue is in a sense good news - the research has found its way to other journals (e.g. disease specific or other disciplinary journals) or is in early stages of development; indications of further outreach and development of the science in paediatric palliative care.

The collection of articles in this issue suggests that Paediatric Palliative Care research *has* come of age. That is, high quality investigation to benefit seriously ill children and their families is being conducted across the globe. At the same time, we have a long way to go in research, care and treatment. Indeed, many of the publications featured here show ongoing high suffering in children, their families and the clinicians who care for them and remind us of the work before us if we are to meet the challenge of reducing suffering.

Attaining that bar will require development and implementation of high-quality interventions which are grounded both in a thorough, robust understanding of the problems children, parents and clinicians face and in the complexity of the situations in which they are delivered. The interventions we develop and deliver require attention to the multiple factors that underpin the problems they are designed to ameliorate. That said, we must not allow our pursuit of the perfect, the ideal, to overtake a trial of the good.

We look forward to future issues with studies of the good – an achievable goal given the articles in this issue.