

# Disparities in Pediatric Palliative Care: An Opportunity to Strive for Equity

Kira Bona, MD, MPH,<sup>a,b,c,d</sup> Joanne Wolfe, MD, MPH<sup>a,b,c,d,e</sup>

The importance of pediatric palliative care (PPC) for children with cancer has been broadly embraced over the last 2 decades in response to compelling evidence of high symptom burden and suffering throughout the continuum of care.<sup>1-3</sup> Yet, how best to evaluate the impact of PPC remains a methodological challenge in a field focused on patient-reported outcomes, including symptom alleviation and goal-concordant care.

In adult oncology, the benchmarking of palliative care has been facilitated by data demonstrating that end-of-life (EOL) care intensity (which is evaluable with administrative data, such as hospitalization and receipt of ICU care) is discordant with the wishes of adult patients with cancer.<sup>4,5</sup> Similar benchmarking in pediatrics has been limited by an unknown correlation of care intensity with family goals and an absence of methodology for pediatric-specific administrative data. In this issue of *Pediatrics*, Johnston et al<sup>6</sup> provide the first US population-based data describing rates of care intensity in EOL pediatric oncology. They find that two-thirds of children who died of cancer in California received an intense EOL care intervention<sup>6</sup>; recapitulating a similarly high frequency identified in a Canadian population-based cohort.<sup>7</sup> Whether such care intensity is concordant with the wishes of pediatric patients with cancer and their families is not known.

Perhaps more striking than their methodological contribution is that Johnston et al<sup>6</sup> acknowledge the specter of disparities in PPC, identifying the urgent need to evaluate

equitable access to and efficacy of PPC interventions. They find that underserved children, including underrepresented minorities and those with public insurance, are more likely to experience high-intensity EOL care, including in-hospital death.<sup>6</sup> The authors set a clear path for next investigative steps in the field, namely, determining whether these differences are “consistent with patients’ and families’ preferences or driven by timing of EOL conversations, hospice and palliative care availability, or other factors.”<sup>6</sup> Perhaps it is all 4 of those things. Little is known about equity in the provision of PPC. Do underserved children have similar rates of access to PPC? When PPC is provided to underserved children, do they derive the same benefits with regard to advanced care planning, symptom management, and quality of life?

In a 2008 systematic review of mechanisms underlying differences or disparities in PPC, Linton and Feudtner<sup>8</sup> delineated disparities as differences in health care not due to patient preferences or the appropriateness of intervention. Johnston et al’s<sup>6</sup> finding of systematic differences in EOL care intensity for underserved children thus calls for investigation of both preference-driven variability and social context-driven disparities.

Both underrepresented minorities and publically insured children share the following common burden: a higher likelihood of living in an impoverished home. In fact, 1 in 5 children in the United States lives in poverty,<sup>9</sup> and although little is known about poverty



<sup>a</sup>Department of Medicine, Boston Children’s Hospital, Boston, Massachusetts; <sup>b</sup>Division of Population Sciences, Departments of <sup>c</sup>Pediatric Oncology and <sup>e</sup>Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, Boston, Massachusetts; and <sup>d</sup>Harvard Medical School, Harvard University, Boston, Massachusetts

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Address correspondence to Kira Bona, MD, MPH, Department of Pediatric Oncology, Dana-Farber Cancer Institute, 450 Brookline Ave, Boston, MA 02115. E-mail: kira.bona@childrens.harvard.edu

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and PPC,<sup>8</sup> we do know poor children experience disparities in access to general pediatric health care as well as inferior general pediatric health outcomes.<sup>10</sup> How might family poverty impact EOL care intensity? PPC is a limited resource, dependent on nonstandardized referral patterns and available primarily at larger academic centers.<sup>11</sup> It is plausible that children from low-income homes or neighborhoods receive care at centers with limited PPC. If we hypothesize that receipt of PPC services results in lower-intensity EOL care, this might drive the observed difference. However, it is worth considering that regardless of whether they receive PPC consultation, poor families may feel less able to support a child dying of cancer at home, and this may in turn impact family goals and preferences. Perhaps in-hospital death, and the correlate of higher-intensity EOL measures, reflects

family preference in the context of socioeconomic disparities. Previous studies have demonstrated that children with complex chronic illnesses who live in more affluent neighborhoods are more likely to die at home.<sup>12</sup> Contributing factors to this finding may include the fact that pharmacies in racial and/or ethnic minority neighborhoods (which are disproportionately low income in the United States) are significantly less likely to stock pain medications than those in other neighborhoods,<sup>13</sup> and home care services (eg, nursing and medical equipment) may not be available in low-income areas.<sup>14</sup> It is additionally plausible that insufficient concrete household resources may contribute to parental decision-making in the advanced illness setting.<sup>15</sup> For example, a mother who is skipping meals to ensure her children are fed or who knows that the heat has been turned off may have

valid concerns about bringing her child home to die. Neither pediatric oncology nor PPC currently address such possible drivers of EOL outcome in a systematic fashion.

As clinicians in pediatric oncology and palliative care, we strive to provide comfort and care concordant with the goals of the families we serve. Johnston et al<sup>6</sup> provide a methodological framework to help us begin benchmarking our successes. More importantly, they highlight the opportunity we cannot afford to miss, ensuring that our successes are equitably distributed across all children for whom we care.

#### ABBREVIATIONS

EOL: end of life

PPC: pediatric palliative care

**COMPANION PAPER:** A companion to this article can be found online at [www.pediatrics.org/cgi/doi/10.1542/peds.2017-0671](http://www.pediatrics.org/cgi/doi/10.1542/peds.2017-0671).

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