

# Editorials

## Encouraging Family Physicians to Fill the Gaps in Hospice and Palliative Care for Children

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**I was asked** to partner with my organization's hospice medical director to support an infant needing end-of-life care during the last month of my hospice and palliative medicine fellowship. A children's hospital more than 60 miles away contacted our hospice agency to consider admission for an infant with a severe heart condition. The pediatric cardiologists had reached the limits of what surgeries and medications could do and recommended hospice to support the patient and family at home during the last few months of life. Unfortunately, no hospice agencies in the patient's rural hometown cared for children.

There is a lack of physicians with training in caring for children with serious illnesses who also work with hospice agencies.<sup>1-3</sup> A previous editorial in *American Family Physician* discusses why "...family physicians are in a unique position to champion this philosophy of terminal care."<sup>4</sup> Family physicians provide care throughout a person's entire life span, emphasize strong, trusting relationships with families, and embrace interdisciplinary teams, all values that align with the philosophy of hospice and palliative care.

In the United States, an estimated 500,000 children live with a serious or complex illness, approximately 45,000 of whom die annually, most often in a hospital setting.<sup>1,3,5-7</sup> Hospice for children can improve physical symptoms, alleviate psychosocial stressors, and provide spiritual support for the entire family.<sup>7,8</sup> Hospice shifts the focus of care from curing a disease to alleviating suffering and allowing children to live as well as possible for as long as possible.<sup>4</sup> Although more than 70% of families prefer their home as the location of death, up to 90% of children who qualify for home hospice care never receive it.<sup>1,3,5-8</sup> This disparity is prominent in rural areas.<sup>1,3</sup> Common barriers to hospice care for children include a lack of access to programs that include children, confusion about the intent and scope of hospice services, less predictable prognoses in children, difficulty

accepting an incurable prognosis in children, lack of nursing staff trained to care for children, physician discomfort with end-of-life discussions, and a limited number of clinicians who provide symptom management and end-of-life care to children.<sup>1-3,7,9-11</sup>

The American Academy of Pediatrics and the World Health Organization recommend early and accessible hospice and palliative care for children with complex chronic, life-limiting illnesses.<sup>3,6,10-12</sup> However, only 40% of hospice agencies report being able to provide these services.<sup>8</sup> The Affordable Care Act states that patients younger than 21 years of age who have a terminal prognosis and a life expectancy of six months or less can receive disease-directed interventions and hospice services concurrently.<sup>6,13</sup> But many agencies care for just a few children per year and do not have dedicated services for children.<sup>14,15</sup> The number of hospice agencies providing services to children continues to decline.<sup>5,7,8,14</sup>

A survey of hospice and palliative medicine fellows in the United States who completed training in 2018 showed that 47% completed their primary residency in internal medicine, 18% in family medicine, 12% in pediatrics, and 5% in emergency medicine.<sup>16</sup> Few institutions provide specialized training for children in this field. In 2020, only 13 of the 159 hospice and palliative medicine fellowship programs reported having dedicated training programs for pediatricians, with just 17 fellows graduating from these programs each year.<sup>17</sup> Additionally, most pediatricians are accustomed to caring for patients who typically recover from an illness, and only large cities have enough population density to justify employing a full-time, formally trained hospice and palliative medicine pediatrician.<sup>15</sup>

Organizations such as the Center to Advance Palliative Care and the Northwest Pediatric Palliative Care Coalition are working on coalitions or training sessions with pediatric specialists to support clinicians and overcome barriers to

end-of-life care for children.<sup>1,8,18,19</sup> However, these efforts may not be enough to fill the gaps.

The philosophy and scope of family medicine position us to provide high-quality, end-of-life care for our patients, specifically children. Family physicians can be involved in several ways, such as joining a coalition to help support hospice programs in the care of children. In the same way a family physician can continue to be a patient's primary physician when the patient begins living at a nursing home, a family physician can also continue to be a patient's primary physician when the patient begins receiving hospice care (i.e., the attending of record). In this scenario, hospice nursing staff first call the designated primary physician for any questions or concerns before calling the hospice physician.<sup>20</sup> Family physicians can also consider becoming certified to serve as hospice medical directors, a process that does not require fellowship training (<http://aahpm.org/certification/hmdcb>). Physician positions with hospice agencies are often part-time.

Hospice and palliative medicine specialists should seek opportunities to be involved in the education of family medicine residents. This mentorship may inspire others to develop the skills to care for their patients at the end of life. Options for more extensive training include completing a graduate certificate (<http://aahpm.org/training/advanced-training>), a master's degree, or a hospice and palliative medicine fellowship. By using the full scope of care to include comfort-focused care for children, family physicians can continue to serve as patients' primary care physicians through the end of life and demonstrate their commitment to their local communities.

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