

# Concurrent Care Is Not Enough: More Hospice Reforms Are Needed for Children with Serious Illness



Life-limiting diseases have been increasingly prevalent in children. Because of this trend, Grossoehme et al address in this volume of *The Journal* an emerging and relatively underdescribed domain of services for children with serious illness: home-based hospice and palliative care.<sup>1</sup> They report on a collaboration between 3 major children's hospitals in Ohio, each with comprehensive hospital- and home-based palliative care (HBPC) services. After describing a cohort of 206 children referred to either HBPC or hospice, they conclude that “the notion of ‘hospice’ vs ‘palliative care’ may be a false dichotomy in children with life-limiting conditions.”<sup>1</sup>

The cliché that “children are not just little adults” is particularly apt in this corner of the health policy world relating to eligibility for hospice services. Children are still often required to meet hospice eligibility criteria that were originally created for Medicare beneficiaries, that is, patients must have a terminal diagnosis with a prognosis of 6 months or less “if the disease runs its normal course” and must forgo “curative therapies” for that terminal diagnosis.<sup>2</sup> As a result of applying this standard to children, very few of them receive the benefits of hospice care.<sup>3</sup>

The first, and potentially greatest, barrier to meeting hospice eligibility for children is the requirement to stop “curative” treatments (which may be more appropriately called “disease-directed” if or when cure is not possible). For many families and their pediatric providers, letting the disease “run its natural course” rarely feels like the right thing to do. In some cases, disease-directed treatments can prolong a relatively good quality of life, and in other cases any prolongation of life, at any cost, is very much desired by families. Although beyond the scope of this discussion, these same medical and psychological factors have also kept many adults out of receiving hospice services until very late in the disease course.

Section 2302 of the Patient Protection and Affordable Care Act of 2010 opened the option for hospice care to many more children with serious illness by allowing patients under 21 years of age with public insurance to receive hospice services “concurrent” with curative therapies.<sup>2</sup> Although this regulatory change was certainly a big step forward, the impact has been mitigated for several reasons.<sup>4</sup> First, concurrent care is still not an option for many children covered by private insurance, because some employer-based health plans will not (and are not required to) accommodate this arrangement. In addition, implementation of the concurrent policy has been delayed in some areas of the country, limiting access to

children with public coverage. Perhaps most significantly, many localities lack hospice services with both the willingness and capacity to serve children, an issue that needs to be continually addressed, even when all the eligibility-related restrictions are removed.

Beyond the requirement to stop disease-directed treatments, the 6-month or less prognosis requirement is an additional barrier to children receiving hospice services. Although not always straightforward, clinicians for adults can use prognostic formulas to help understand whether time might be short enough to refer an appropriate patient to hospice (eg, <https://eprognosis.ucsf.edu/ppp.php?p=hospice>). Creating these prediction algorithms requires large numbers of patients with a limited number of diagnoses. We have neither of these conditions in pediatrics, where the epidemiology of serious illness is characterized by a relatively small incidence of a wide range of illnesses. Furthermore, children with life-threatening diseases, such as cancer, might live longer than the “terminal diagnosis” alone would suggest, owing to the relative health of their unaffected organs.

This new study from Grossoehme et al provides evidence of the challenge that the prognostic requirement places on pediatric providers in deciding what home-based program will best serve their patients.<sup>1</sup> Their descriptive, retrospective chart review study describes a cohort of 206 children who were newly enrolled in either home hospice or HBPC in 2016. According to their description, the major difference among whom was referred to hospice vs HBPC was the presence of a meeting the 6-month prognosis hospice criteria. In 2 of the centers, the same teams provided similar services for those in both programs; in the third center, the hospital team provided HBPC while hospice services were provided by community-based hospice programs.

The children in their cohort are like those described in other registries of hospital- and community-based palliative care programs, with the most common diagnoses being genetic or chromosomal (23% overall), cancer or malignancy (21% overall), and neurologic or neuromuscular conditions (23% overall). Although otherwise similar, children in hospice were more likely than those in HBPC to have a malignant condition (41% vs 14%) and those in HBPC were more likely to have prematurity as their primary diagnosis (15% vs 2% of those in hospice). Use of medical technology

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HBPC Home-based palliative care

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was relatively high overall (85%) and in both subgroups. Importantly, over a 19-month follow-up period, 28% of this entire cohort died ( $n = 57$  children), and even though the majority of those who died (67%) were in hospice, 35% (20/57) of the decedents were enrolled in HBPC. Furthermore, 40% of these 20 children (8/20) died at home. The authors note that this is a higher death rate than has been seen in adults who receive community-based palliative care.

Beyond the challenge of accurately predicting prognosis, Grossoehme et al describe potential reasons that those who died in HBPC may not have chosen hospice care.<sup>1</sup> In some cases, although a child might be eligible, a family might not be willing to accept the concept of hospice for their child. Additionally, some families may not have had the option of concurrent hospice care (eg, their private insurance would not cover such), and not wanting to stop disease directed treatment, they chose HBPC.

Given that many of the providers and services are the same for both home-based programs in Ohio, we might assume that those who died at home without hospice received the medical and psychosocial support that they needed at the end of life. However, this assumption would not hold in communities where the 2 sets of services and providers are distinct, and children in those areas are at risk for having multiple unmet care needs.

With the unique features of the HPBC and hospice programs in Ohio and the limitations of their retrospective data set, Grossoehme et al are not able to provide additional evidence to bolster their argument for the “false dichotomy” between pediatric hospice and HBPC services.<sup>1</sup> And yet because of the overlapping services, in this Ohio network, the decision to refer to hospice may hinge more specifically on prognosis than it would in other parts of the country. This allows the authors to demonstrate more clearly than others that ultimately there is simply 1 population of children who need a diverse and changing set of services. Additional data from other parts of the country are required to document all the many challenges that can come with dividing children into 2 groups of those needing hospice vs HBPC services.<sup>4</sup>

Children with serious illness and their families should have the ability to spend as much time as possible in their homes

and communities, without sacrificing the psychosocial, nursing, and medical care that they need. And, they should have the choice to die at home with as much support as possible, if that is preferred. Concurrent hospice care provisions were a big step toward addressing a major barrier to hospice services for some but not all children; however, the stipulation of a short prognosis, payor reluctance, and unavailability of services continue to be barriers. As Grossoehme et al describe, it is time to create hospice and palliative care programs modeled on the needs of children, not adults. While learning more about the challenges of current systems, the pediatric palliative care community must come together to identify ways to structure and finance home-based hospice and palliative care for children with serious illness to ensure uninterrupted, child- and family-centered care. ■

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