

PERSPECTIVE



Choiceless options: when hospital-based services represent the only palliative care offering

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Lack of availability of community-based pediatric palliative care and home-based hospice services for children limits care location options for families. For many families from rural regions, hospital-based care models may be perceived as the only viable choice due to geographic gaps in service coverage. Gaps exist not only in access to these key services but also in service quality without national pediatric service standards. While families from rural regions may express a goal to be home with their child for relational and communal care purposes the current setting of services may limit the feasibility of home-based care. Several potential pediatric systems changes (workforce, finance, policy) have the capacity to create and sustain a care model that allows a child with complex, chronic, or life-limiting diagnoses to experience a home other than the hospital. The existence of community-based pediatric palliative and pediatric home-based hospice services with a sustained workforce and high-quality national standard for children would bolster the ultimate congruence of a family's preference with actual care choices.

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IMPACT:

- Families of children with life-limiting diagnoses may express a preference to be home together.
- Disparities in access to community-based pediatric palliative care and hospice exist for children, particularly in rural regions.
- These gaps may translate into families experiencing hospital-based settings as the only feasible care model which may result in care escalations and medicalization.
- Expansion of the community-based workforce and development of pediatric-specific standards for key palliative services would increase home-based care options for families.
- This paper acknowledges the pediatric palliative and hospice availability crisis in rural regions and urges for improved access to high-quality, community-based services for children.

CASE VIGNETTE

A hospital-based palliative care team was consulted to review care options with a family considering returning to their rural home for a cherished family time supported by home-based hospice services. With or without heart surgery, their baby boy was not expected to survive his second birthday due to a complex genetic condition. Both parents emphasized their hope was for their son to sleep in his cowboy-decorated home nursery rather than an intensive care crib and they wanted him to wake to the sound of his siblings playing not hospital machines beeping.

In seeking to enroll the family in home-based support services, the palliative care team communicated with eight hospice and community-based palliative agencies. Each shared a desire to assist, but was unable because the family's residence was outside of the hospice's service catchment region. The only viable offering identified was an adult-based skilled nursing facility. A private duty nurse without pediatric training offered to check-in on the baby three scheduled afternoons per week. The parents recognized that the nursing facility would not sufficiently attend to their son's medical needs or their larger psychosocial support needs such as mental health screening, spiritual support, siblings

anticipatory grief preparation, legacy-making activities, etc.¹ Inability to locate pediatric-trained personnel nearby, absence of an interdisciplinary care model such as chaplain and social work via hospice care, and lack of access to a 24/7 nursing contact led the family to conclude that bring their son home would result in aloneness and even abandonment.

While the hospital-based palliative care team was researching home-based care options and continually updating the family on creative case management attempts without avail, the intensivists and cardiologists were daily updating the family on biomedical intervention offerings such as converting the nasogastric (NG) tube to gastrostomy tube and an initial cardiac surgical procedure in a multi-staged-surgical approach. Both parents continued to voice concern that their focus was the relational quality of life together as a family at home and feared "getting stuck" in the hospital. The baby's father tearfully shared that they were facing "choices without real options since home support is not available to the extent that would be helpful or supportive." The baby's parents eventually decided to pursue surgical interventions with the hope these would "buy time" for their son to grow and get closer to home. Ideally, the cardiac surgery would make their son

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less reliant on supplemental oxygen and positive pressure ventilation and the gastrostomy tube would minimize the risk of dislodged NG tube at odd hours in the evening at home.

For the family in the case vignette, their loved son underwent his first surgery and then experienced a cascade of medicalized procedures and interventions which included extensive laboratory work-ups, total parental nutrition with slow attempts to gavage feeds, multiple rounds of antibiotics, respiratory support escalation, and frequent returns to the operating room. He remained inpatient for many months. His siblings visited on the weekends and his nursing staff decorated his room with a farm theme to foster a sense of connection with home. His parents took turns at his bedside, driving more than four hours one-way between their farm and the hospital, a drive complicated by his dad's longer work hours during harvest and snowy roads in early winter. The baby did experience knowing his family's love and devotion although he did not make it home.

CURRENT PROBLEM

Rural children with life-limiting illnesses and their families have two main bridges to cross in order to get and stay home: (1) access to community-based pediatric palliative care for early integration from the time of diagnoses through cure or end of life and (2) access to pediatric hospice for the final 6 months of life. Community-based pediatric palliative care is integral in the coordination and provision of complex care for children.² Community palliative care services are limited to nonexistent.³⁻⁵ Only a quarter of the pediatric oncology centers in the United States offer pediatric patients referrals to community-based palliative care.³

Pediatric home-based hospice consists of a variety of services for pain and symptom management and bereavement, generally reimbursed at a limited per diem rate and provided by an interprofessional group of physicians and advance practitioners, nurses, and other key personnel, such as chaplains, nutritionists, therapists, health aides, and bereavement counselors in the final 6 months of life.⁶ Access to home-based hospice services is also sparse. Families must rely on adult-based hospice teams clustered around city settings.^{7,8} The passage of the 2010 Affordable Care Act Concurrent Care for Children Requirement allows any Medicaid child who is eligible for hospice care to also have all other services that are related to the treatment of the child's condition provided. Despite this Medicaid-based progress in the payment provision, there remains a paucity in available concurrent service offerings for children in certain geographies.

Too many families in rural regions note a lack of bridges between the hospital and home.⁹ The increasing number of families preferring to have their child with life-limiting illness spend their days at home rather than within a hospital¹⁰ heightens concern about the inability for families to be "good parents"¹¹ in the setting most preferred by the child and family.¹² High-quality community-based care provides the advantage of honoring the family's preference for location and togetherness, attaining a higher quality of life, and managing symptom burden in a comfortable setting for the child.¹³⁻¹⁵ Inability to access high-quality community-based care at the end of life risks negatively impacting the child's pain burden¹⁶ and perception of symptom management,¹⁷ family memory-making,¹⁸ moments of play and fun,¹⁹ and ultimately caregiver bereavement.²⁰

CONCERNS WITH THE CURRENT STATE OF CARE

Lack of access to community-based quality pediatric or hospice care blocks the bridge to home for rural children and families and restricts care delivery to hospital-based settings. One consequence of this approach is an increase in moral distress among hospital staff because of the unsettling escalations of biomedical interventions,

such as tracheostomy and ventilator, central lines, surgeries, or gastrostomy tubes despite the known landscape of poor prognosis for the child.^{21,22} And yet, families from rural areas which lack community-based support services may find themselves with only the hospitalized model of care escalation as a viable option. For the child, this equates to extended hospital stays with a sprinkling of intensive care inpatient days. Hospital-based care models all too frequently cascade into one medical procedure leading to the next or one clinical complication leading to the next biomedical intervention.²¹

An alternative consequence is that for those rural children and families who are able to cross the bridge between inpatient and home-based care, there are usually complications in providing home-based services.²³ Several concerns focus on the lack of quality standards for pediatric patients enrolled in-home hospice and the inadequacy of pediatric-trained hospice providers.²⁴⁻²⁶ Children who receive care from local hospices in their community often receive services from caring nurses who lack training, experience, and comfort in the provision of palliative and hospice care to pediatric patients.²⁷ There is a risk of highly compassionate but possibly pediatric-incompetent care if there is not an existing mechanism for proactive training and sustained child-specific symptom support for staff.²⁸ Based on clinical experience with families who were discharged to home in a rural setting with hospice services, families may experience no supportive presence in the home. For example, children can be sent home without access to basic feeding mechanism and just with comfort medications and this can cause family distress.

PROPOSED SOLUTIONS

Parents whose children enroll in home-based palliative and hospice programs prioritize compassionate and competent care as priorities.²⁹ We believe that extensive system-level changes would need to occur to enable home-based options for rural children and their families. There is a need to (1) develop a statewide or nationwide pediatric hospice/palliative care partnerships³⁰ and (2) standardize hospice training³¹ (3) create new payment models for palliative care, and (4) leverage telehealth support³² for hospice teams for bridge-building, as these interventions have been affirmed by family caregivers.³³ More specifically, we advocate for an extension of pediatric-specific education for hospice staff and pediatric-specific licensure for hospices. Training and reimbursement for pediatric caregivers matters in growing and supporting the workforce. The lack of national quality and accreditation standards for home hospice and palliative care support specific for pediatric patients results in variable service models, warranting the development of quality indicators co-designed by families.³⁴ Extension of pediatric home-based staffing and development of pediatric care standards are both necessary for children and families to feel well-held at home.

High-quality, accessible community-based palliative care and hospice care for rural children along with larger issues such as pediatric hospice staffing, reimbursement models, national accreditation, and quality standards for hospice could translate into the home. Families will stay or return to the hospital setting without the presence of services to support alternative options. Until the pediatric community addresses the reality that the option is frequently hospital-based medicalization versus feeling abandoned at home by the health care system, then we miss the opportunity to really offer a true choice to children and their families.

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AUTHOR CONTRIBUTIONS

M.S.W. co-conceptualized the paper, drafted content for the initial manuscript, and reviewed and revised the manuscript for intellectual content. L.C.L. co-conceptualized the paper, made substantial editorial contributions, and reviewed and revised the manuscript for intellectual content.

COMPETING INTERESTS

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CONSENT STATEMENT

Patient consent is not required. All identifiers were removed from the case vignette, which represents a compilation of case scenarios in one de-identified scenario.

ADDITIONAL INFORMATION

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