

Intensity of Healthcare Utilization Among Pediatric Hospice Patients Receiving Concurrent Care

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ABSTRACT

BACKGROUND: As children with life-threatening conditions near end-of-life, their disease burden and care requirements tend to increase, leading to high intensity of care in the hospital. Previous studies have examined patterns of healthcare usage among these children receiving hospice, but little is known about the impact of pediatric hospice involvement on healthcare utilization compared with usual care. We aimed to examine whether pediatric patients enrolled on concurrent hospice care utilize healthcare services at the same rate as prior to hospice enrollment.

METHODS: A retrospective chart review examined deceased pediatric patients enrolled on the HopeHealth pediatric hospice between January 1, 2022 to December 31, 2023 who had received hospice care for more than seven days and who spent at least one day on hospice out of the hospital. We compared the number of hospital admissions and ICU days during the period between hospice enrollment and death (post-hospice) to the equivalent duration of time prior to hospice enrollment (pre-hospice).

PRIMARY RESULTS: All patients had fewer hospital days and PICU days post-hospice compared to pre-hospice. Nine patients had no hospital days following hospice enrollment, of which four had had zero hospital days prior to hospice enrollment.

PRINCIPAL CONCLUSIONS: In this single-center study, patients receiving concurrent hospice care had fewer hospital days, ICU days, and invasive procedures compared to during the equivalent duration of time prior to hospice enrollment. Provision of hospice support alongside continued disease-directed care may lead to decreased inpatient admissions and interventions. More study is needed to better understand this potential correlation.

KEYWORDS: hospice; concurrent care; pediatric end-of-life

BACKGROUND

Children with life-limiting or terminal conditions often experience increased intensity of care as they near end-of-life (EOL).^{1,2} However, this level of care is not always consistent with the goals or wishes of the child and family. The goals of pediatric palliative and hospice care are to enhance the quality of life for a child and family living with life-threatening conditions, prevent and minimize suffering, and facilitate medical care that is concordant with their hopes and values.³ Further, Section 2302 of the Affordable Care Act removed prior barriers to hospice care for children insured by Medicaid or Children's Health Insurance Program (CHIP) by allowing for concurrent care, through which children with a terminal condition may continue receiving disease-directed treatment alongside the support and comfort-focused care of hospice.⁴ Many commercial insurance providers follow this model as well.⁵ There is an expanding body of data to support the need for psychosocial support in this population,⁶ and examining patterns of healthcare utilization among children receiving hospice.^{7,8} However, recent assessments reveal persistent misunderstandings and lack of clarity among clinicians, families, and hospice agencies regarding the concurrent care benefit.⁹

In order to better understand the impact of hospice support on intensity of care in our region, we examined patients who received hospice care through a dedicated pediatric hospice team, focusing on healthcare utilization as measured by number of hospitalizations, days spent in intensive care, and Emergency Department visits prior to and after hospice enrollment. Our hope is that understanding these patterns may facilitate evidence-based allocation of resources for pediatric hospice programs and improve overall care of children and their families at end-of-life.

OBJECTIVES

The objectives of this study were:

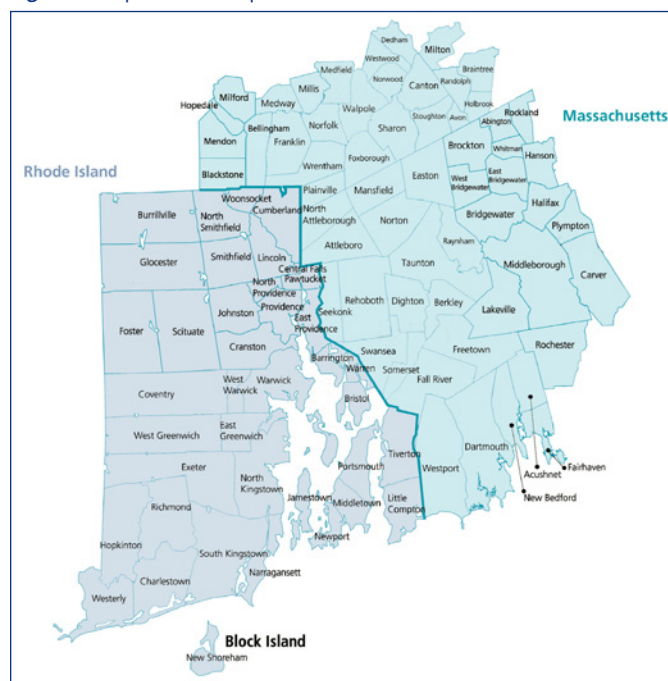
- To compare the rate of healthcare utilization among terminally ill children after enrollment on concurrent hospice care as compared to during the same length of time prior to hospice enrollment.
- To share the experience of one hospice organization providing hospice care concurrently alongside disease-directed interventions.

METHODS

We performed a retrospective analysis of pediatric patients enrolled on concurrent hospice care through a single institution between January 1, 2022 and December 31, 2023, who subsequently died. HopeHealth, the nation's second-oldest hospice organization, serves patients throughout Rhode Island and southeastern Massachusetts [Figure 1] and developed a dedicated pediatric team in 2022. Patients under age 21 years are eligible for concurrent care in Massachusetts; the age limit has been extended to 26 years in Rhode Island. Exclusion criteria for the study included hospice enrollment less than seven days prior to death, revocation of hospice services prior to death, and zero days spent at home while enrolled in hospice. Additionally, despite the provision of concurrent care, hospitalization at institutions outside of HopeHealth's service area [Figure 1] necessitates discharge from hospice; thus, patients who were hospitalized at institutions outside of Rhode Island and southeastern Massachusetts were not included, both due to this disruption in hospice service and unavailability of data from outside institutions [Figure 2].

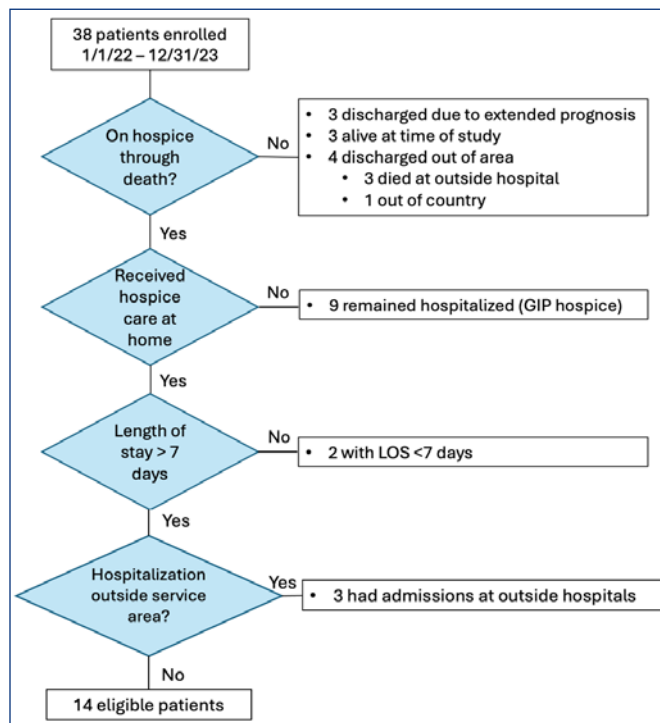
The post-hospice period was defined as the number of days between hospice enrollment and death. The pre-hospice period was the same duration of time prior to hospice enrollment, or between birth and hospice enrollment if shorter. We examined healthcare utilization within the post-hospice period and pre-hospice period, comparing the number of hospital admissions, Emergency Department visits at Women and Infants Hospital or Hasbro Children's (the

Figure 1. HopeHealth Hospice Service Area



<https://www.hopehealthco.org/where-we-help>

Figure 2. Identification of Eligible Patients



only hospitals within HopeHealth's service area at which the included patients received care) within each time period. This study was given non-research designation by the Brown University Health IRB.

Analysis

Data from pre- and post-hospice periods were manually extracted from the electronic medical records (EMR), including the number of hospital days, ICU days, and the number of Emergency Department visits.

RESULTS

Thirty-eight patients had enrolled on the pediatric hospice service during the study period. Fourteen fit the eligibility criteria [Figure 2]. Demographics and clinical characteristics are described in Table 1. Average patient age at time of enrollment was eight years and from three days to 22 years. Nine patients were male and five patients were female. The most common class of diagnosis was an oncologic disorder (57%).

Over the study period, all patients had equal or fewer total hospital days and fewer total ICU days during the post-hospice period compared to the pre-hospice period [Figure 3]. Nine patients had no hospital admissions following hospice enrollment. Of these, six had also zero hospital days prior to hospice enrollment. In these six cases, hospice enrollment was initiated in the outpatient setting and the duration of each patient's survival post-enrollment was shorter than

Table 1. Demographics and Clinical Characteristics of Eligible Patients

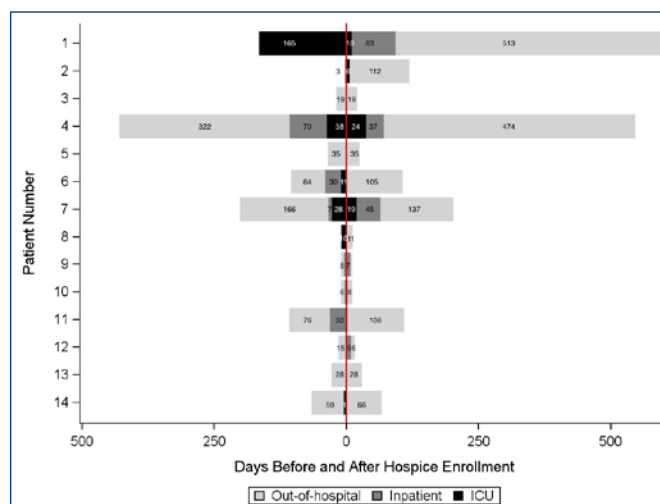
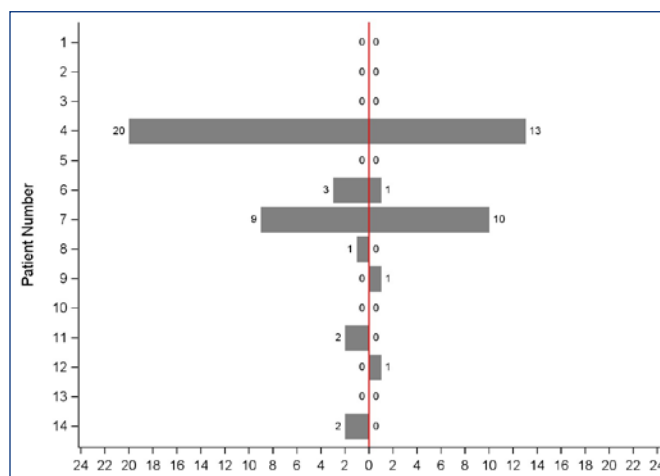
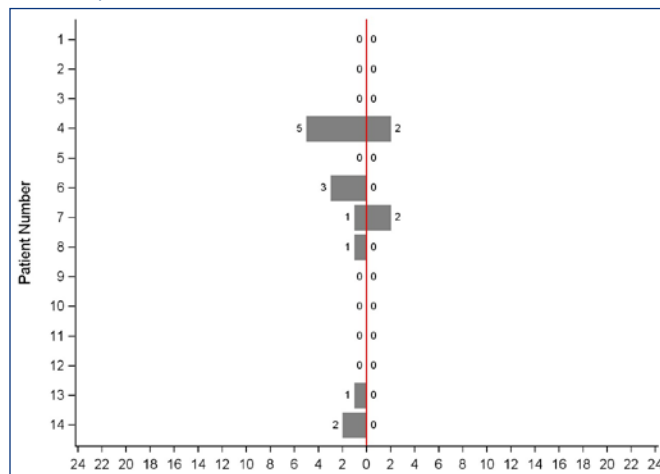
Patient #	Age at Hospice Enrollment	Sex	Diagnosis Type	Location of Death
1	5 Mo	M	Genetic Disorder	Hospital (Wards)
2	3 D	M	Genetic Disorder	Hospital (PICU)
3	2 Yr 10 Mo	M	Oncology	Inpatient Hospice
4	1 Yr 2 Mo	F	Neurological Disorder	Inpatient Hospice
5	7 Yr 3 Mo	M	Oncology	Home
6	12 Yr 4 Mo	F	Oncology	Home
7	12 Yr 3 Mo	M	Cardiomyopathy	Hospital (Wards)
8	4 Yr 4 Mo	M	Oncology	Home
9	15 Yr 10 Mo	M	Oncology	Hospital (Wards)
10	19 Yr 10 Mo	M	Oncology	Hospital (Wards)
11	22 Yr 7 Mo	F	Oncology	Inpatient Hospice
12	11 Yr 8 Mo	F	Genetic Disorder	Home
13	2 Yr 3 Mo	M	Oncology	Home
14	7 Yr 3 Mo	F	Neurological Disorder	Home

the length of time that elapsed between their last hospitalization and their hospice enrollment. Almost all patients had equal or fewer total hospital admissions [Figure 4] and Emergency Department visits [Figure 5] in the post-hospice period compared to the pre-hospice period.

DISCUSSION

Children with life-limiting or terminal conditions often experience increased intensity of care at EOL. Hospital admissions and Emergency Department visits are often psychosocially disruptive to patients and families and increasingly costly; as of 2019, the average cost of a pediatric hospitalization involving ICU care had nearly doubled since 2001.¹⁰ While the Affordable Care Act allows for ongoing disease-directed care and interventions alongside hospice support, it is not yet clear what impact concurrent care has on the frequency or intensity of disease-directed care.

The current study serves as a first step in exploring the impact of concurrent hospice care on the use of disease-directed interventions. The results demonstrated that pediatric patients receiving concurrent hospice care spent the same number or fewer days in the hospital and fewer days in the ICU after hospice enrollment compared to the equivalent duration of time prior to enrollment. Nearly all had fewer or no hospital admissions after enrolling in hospice and most had fewer Emergency Department visits. This suggests that patients and their families were able to spend more time at home and that the overall costs of care may have decreased compared to continuing care without hospice involvement.

Figure 3. Cumulative In-Hospital, ICU, and Out-of-Hospital Days Before and After Hospice Enrollment**Figure 4.** Total Numbers of Inpatient Admissions Before and After Hospice Enrollment**Figure 5.** Total Numbers of Emergency Department Visits Before and After Hospice Enrollment

This study was limited in that it examined patients within a single hospice agency and results may not be generalizable to other populations. Due to its small size, it was not adequately powered to assess the statistical significance of these results. Enrollment was also limited by the requirement that patients had spent time at home after hospice enrollment; this criterion was used deliberately to eliminate patients whose only time on hospice was while receiving general inpatient level of hospice care in the hospital, typically following an acute injury or illness.

We utilized patients' time prior to hospice enrollment as a control against which to compare their time receiving concurrent care, which poses several challenges. Patients who enrolled on hospice shortly after birth did not have an equivalent period of "pre-hospice" time to examine. Further, we speculate that healthcare utilization would have continued at the same intensity through EOL if patients had not enrolled on hospice, though it is possible that patients' and families' goals may have evolved in that time even without hospice involvement, still leading to decreased healthcare utilization. Still, literature over the past 20 years has consistently shown that children dying from a variety of conditions continue to suffer significant symptoms,^{11,12} and more recent studies illustrate a continued use of high-intensity care at the end of life in pediatric patients with terminal diagnoses,¹³ lending credence to the assumption that intensity of care would not have declined without hospice involvement.

CONCLUSIONS

In this single-center study, pediatric patients receiving concurrent hospice care had the same or fewer hospital days and Emergency Department visits and fewer total ICU days during their time on hospice compared to the equivalent duration of time prior to hospice enrollment. Provision of hospice support alongside continued disease-directed care may lead to decreased inpatient admissions and interventions and, as a result, fewer healthcare expenditures. More study is needed to better understand this correlation and the degree of potential impact.

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Disclosures

Funding: Not applicable

Conflicts of interest/Competing interests: The authors declare that they have no conflicts of interest relevant to this study.

Ethics approval: Not applicable

Consent to participate: Not applicable

Consent for publication: Not applicable

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