



Published in final edited form as:

J Pediatr Hematol Oncol. 2015 July ; 37(5): 373–377. doi:10.1097/MPH.0000000000000331.

Hospice Care for Children With Cancer: Where Do These Children Die?

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Summary

Hospice is an important provider of end of life care; many children who die of cancer enroll in hospice programs. How frequently such children remain in hospice to die at home, or disenroll from hospice and die in the hospital, has not been described. A child's location of death has important implications for quality of life and parental adaptation. This represents a subanalysis of a retrospective study of 202 consecutive oncology patients who died at a single center between January 1, 2006 and December 31, 2010. Of 95 children who enrolled in hospice, 82 had known location of death. Sixty (73%) died at home or an inpatient hospice unit, 15 (18%) died in the oncology unit, 5 (6%) died in the intensive care unit, and 2 (2%) died in the emergency department. The median length of hospice services was 41 days, twice the national median of 21 days reported in adults. One quarter of children disenrolled from hospice care, ultimately dying in an acute care setting. Further studies are warranted to explore the hospice experience in children, and to address modifiable factors that may impact a family's choice to withdraw from hospice care.

Keywords

pediatric oncology; pediatric palliative medicine; pediatric end of life care; pediatric hospice

Cancer is the leading cause of death due to disease in childhood. The location of death of children with chronic conditions has important implications, and can have a major impact on

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The authors declare no conflict of interest.

the quality of life at the end of life (EOL) and on parental adaptation after a child's death.^{1,2} Dying at home has been signaled as an indicator of good quality EOL care.³ When compared with parents of children who died in the hospital, parents who chose home care more quickly adapted to normal social functioning, more commonly reported that the death at home positively affected their marriage, and experienced significantly less guilt over time than parents who did not choose home death.² These parents also more commonly reported that the death was ultimately a positive experience and that their beliefs regarding the meaning of life and death had not been affected or had been affected positively.² Hospice providers are uniquely suited to facilitate EOL care outside of the hospital setting for both children and adults. Hospice enrollment and hospice care, provided in an inpatient hospice unit or in a patient's home, may enhance the quality of EOL care and influence the location of death. Yet data regarding pediatric hospice enrollment are lacking; the frequency with which children with cancer enroll in hospice nationally, and parental satisfaction with hospice care, are unknown.

Published data suggest that children with brain and solid tumors are more likely to die of progressive disease and to die at home than children with leukemia and other malignancies.⁴⁻⁶ Latino children with cancer have been found to be more likely to enroll in hospice than children of other races.⁷ Two studies have reported that after the introduction of a palliative care team, hospice discussions occurred more often and earlier in children with cancer, and death in the intensive care unit (ICU) or other hospital settings decreased significantly.^{8,9} Although the locations of death in children with cancer and other complex chronic conditions have been reported, the impact of hospice enrollment and retention in a hospice program on the site of death has not been described.^{1,3,4,6,10-16} Therefore, the primary aim of this report is to describe the location of death in a cohort of children with cancer who enrolled in hospice, the factors significantly associated with death at home, and trends in hospice retention in this cohort.

MATERIALS AND METHODS

Approval was obtained from the University of Texas Southwestern Medical Center Institutional Review Board before data collection. This represents a subanalysis of a retrospective cohort study of oncology patients who died in our institution between January 1, 2006 and December 31, 2010. Methods have been previously described.⁷ Patients were identified through review of the institutional cancer and neuro-oncology databases. Inclusion criteria and exclusion criteria were as follows. Inclusion criteria: (1) patients followed in our program for cancer or bone marrow transplant who died between January 1, 2006 and December 31, 2010.⁷ Exclusion criteria: (1) patients above 18 years at the time of cancer diagnosis, (2) death unrelated to cancer or complications of cancer treatment (ie, death due to trauma in patients previously treated for cancer), (3) death in the hospital due to an acute process, in a child for whom a hospice referral would never have been appropriate, for example, a child with leukemia in first complete remission whose death was secondary to sepsis, (4) enrollment in hospice before cancer diagnosis, (5) transfer of care to another nonhospice facility, (6) patients without a diagnosis of cancer, and (7) if oncology or bone marrow transplant was not the primary service, for example, a solid organ transplant patient with posttransplant lymphoproliferative disorder followed primarily by cardiology.⁷ Among

those excluded, the most common reason was death due to an acute process such as sepsis, treatment complications, or complications related to primary disease (N = 46); the second most common reason was transfer of care to another facility (N = 18).⁷ Databases of Hospice of East Texas (HOET) and Community Hospice of Texas (CHOT), the 2 primary hospice organizations to which our program refers patients, were also queried for all children who died during the same time period and cross-referenced with referring oncologists in our program to identify any additional patients.⁷ Hospice enrollment was defined as the patient having enrolled in hospice with either CHOT or HOET, and having received inpatient hospice unit and/or outpatient home-based services from one of these 2 organizations.⁷ “End of life conversation” was defined as any documentation in the inpatient and/or outpatient medical record of a conversation between medical providers and the family regarding the child’s terminal prognosis, goals of EOL care, hospice enrollment, or Do-Not-Resuscitate (DNR) orders.

For the purpose of analysis, race and ethnicity was defined as Latino, white, or other. Religion was defined as Catholic; Protestant, Christian, and Nondenominational; or other. Payor status was defined as Medicaid, Private Pay, and Children with Special Healthcare Needs (indigent healthcare); or Private Insurance and Military Insurance. Diagnosis was defined as leukemia, lymphoma, CNS malignancy, or a solid tumor. End of life conversations were grouped as 0 to 2 or >3.

Two-way associations were tested using χ^2 statistics, and 2-way associations controlling for additional factors were tested using multiple logistic regression with Firth’s correction for small sample bias.^{17,18} All tests were 2-sided; *P*-values were reported without adjustment for multiple testing. SAS/STAT statistical software, version 9.3, was used for all analyses.

RESULTS

Demographic characteristics of children in this cohort who enrolled in hospice have been previously described and are summarized in Table 1.⁷ Many of our patients, as a large not-for-profit children’s hospital in the southwest, are Hispanic (44%), and the majority do not have private insurance (61%).

The locations of death for the children who were eligible for hospice services are described in Figure 1. Of 114 children with cancer in our division who died between 2006 and 2010 and were considered eligible for hospice services, 95 (83%) enrolled and 19 (17%) never enrolled. Of those who never enrolled, 100% died in the hospital and nearly half died in the ICU. Of the 95 who enrolled in hospice, 37 (39%) disenrolled from hospice at least 1 time. Forty-eight (51%) children continued hospice care through their death, and all of them died at home or at an inpatient hospice facility. Twelve of those who disenrolled from hospice returned and died with hospice services, but 22 did not die in hospice: 5 died in the ICU, 15 died on the oncology floor, and 2 died in the emergency department. All 15 children who died in the inpatient oncology unit received comfort care and had a documented DNR order. The median time from disenrollment to death was 1 day, and ranged from 0 days to 402 days.

Nineteen patients (20%) who enrolled in hospice were receiving chemotherapy at the time of death. In 11 cases the chemotherapy was documented as palliative in intent, in 7 cases the chemotherapy was documented as phase I or II, and in 1 case the chemotherapy was a continuation of the child's current therapy. Nine of these children (47%) died at home, 2 (11%) died in the ICU, 4 (21%) died on the floor, and the location of death was unknown for 4 (21%) of these children.

The time from diagnosis to hospice enrollment, from diagnosis to death, from hospice enrollment to death, and from DNR order to death for the 95 patients who enrolled in hospice are summarized in Table 2. The proportion of patients who died within 7 days of enrollment in hospice was 13%, the proportion who died within 14 days of enrollment was 22%, and the proportion who remained enrolled longer than 180 days was 7%. As to our knowledge no similar hospice data are available for children, these times were selected to allow comparison with available national hospice data of adults. Of the 21 patients who died within 14 days of hospice enrollment, 10 children had leukemia or lymphoma, 6 had brain tumors, and 5 had solid tumors. Of the 7 patients who remained longer than 180 days, 5 children had brain tumors, 1 had a solid tumor, and 1 had leukemia or lymphoma. Excluding the patients who never disenrolled from hospice, the median number of times patients disenrolled was 1; the range was from 1 to 7 times. Multiplied adjusted χ^2 statistics and *P* values for 2-way associations with death at home are summarized in Table 3. None of the variables analyzed was significantly associated with death at home in this cohort.

DISCUSSION

More children die of cancer than any other disease, and parental satisfaction with care seems to be greater with improved adaptation and outcomes when a child is able to die at home.² Similarly, adults with incurable cancer prefer to die at home.¹⁸ Hospice is both a philosophy and a system of care, and in the United States represents a preference for home care and family support as opposed to hospitalized care.^{19,20} To our knowledge, this is the first report to describe trends in the site of death and hospice retention among children with cancer who enroll in hospice programs.

Among the 95 children who enrolled in hospice, only half remained in hospice for the entirety of their EOL care; all of those who remained enrolled died at home or in an inpatient hospice unit. Of those who withdrew from hospice, the majority ultimately died in an acute care setting. Likewise, all of the 19 children who never enrolled in hospice died in an acute care setting. Thus, hospice enrollment and retention in children with cancer is associated with lower rates of acute tertiary health care utilization at the EOL. The factors that impact a family's choice to disenroll from hospice are likely highly varied, and it is difficult to know what motivated each family to return to the hospital. Data from the adult world indicate that the most common reason patients are discharged from hospice alive is "no longer meeting hospice criteria."²¹ As the median time from disenrollment to death was 1 day, and the median number of disenrollments was 1 patient, this seems an unlikely explanation for children in this cohort to leave hospice. Time from disenrollment to death ranged from 0 to 402 days, and 3 patients disenrolled more than 50 days before death; one possibility is that some families desired to continue to pursue curative therapy, as concurrent

care was at that time not covered for children under the hospice benefit. However, 9 children who died at home were receiving chemotherapy at the time of death, and all 15 children who left hospice and who died in the oncology unit received comfort care only with documented DNR orders in place. Therefore, we believe it is more likely that these families had other unmet physical, emotional, psychological, or spiritual needs that were better supported in the hospital setting than at home. Given the high frequency of pain and other symptoms in children dying of cancer,⁴ it is possible that parents returned to the hospital seeking improved pain and symptom management; further studies are warranted to understand factors that impact parental perceptions of hospice care.

To our knowledge, there are no national data that track pediatric hospice utilization and length of service; scant literature is available regarding the prevalence of pediatric hospice use or the characteristics of its users.¹⁶ According to the 2010 report by the National Hospice and Palliative Care Organization, the median length of all-cause hospice service for patients in 2009 was 21.1 days, whereas the median length of hospice services for patients in this cohort was nearly twice that at 41 days.²² The average length of hospice service for all patients was 69.0 days, which is equivalent to that received by patients in our cohort.¹⁹ The proportion of all hospice patients who died or were discharged within 7 days of enrollment was 34.4% and within 14 days was 48.5%, both of which are markedly greater than the 13% and 22% in this cohort who died within those respective time periods.²² Finally the proportion of all patients who remained in hospice >180 days in the 2010 report was 11.8%, which is comparable with the 7% observed in this cohort.²² That those children who remained in hospice at the time of death were enrolled longer, and that fewer died within 1 and 2 weeks compared with the national total patient averages, may reflect improved communication regarding EOL issues in pediatric oncology when compared with adult oncology. However, it may also be a reflection of the lower prevalence of comorbidity in children dying of cancer when compared with adults. Four of 47 children who died at home did not have a DNR order in place, which is reflective of the policies of HOET and CHOT, which did not require a child to have a DNR to enroll in hospice care. The Affordable Care Act now allows for curative care concurrent with hospice care for children with Medicaid; it remains to be seen how this allowance will impact the timing of hospice enrollment for children, median length of services, frequency of withdrawal from hospice, timing and presence of DNR orders or advanced directives, and EOL care overall.²³

None of the variables studied was significantly associated with the likelihood of death at home. We previously reported that race/ethnicity is significantly associated with hospice enrollment in this cohort, with Latino children more likely to enroll in hospice than whites, but race/ethnicity was not significantly associated with death at home in this cohort.⁷ Cultural factors that may impact the ability or preference of a Latino family to remain at home for the death of a child are not well described in the literature; more research is needed to understand factors that may impact any family's choice to return to the hospital for a child's death. It has been reported that children with brain and solid tumors are more likely to die of progressive disease, to enroll in hospice, and to die at home than children with other diagnoses.⁴⁻⁷ As diagnosis was not predictive of death with hospice services in this cohort, those factors that predict death in the hospital may be more similar among diagnosis groups than previously appreciated. Prospective studies are needed to gain a more thorough

understanding of the journeys of families with children who are dying in hospice, and to identify factors that may be amenable to interventions by a hospice or palliative care team before returning to the hospital.

The initiation of a palliative care service has also been associated with increased communication regarding EOL preferences in children with cancer.^{8,24} We did not find a relationship between death at home and palliative care consult in this cohort. In our institution, however, referral to hospice remains the responsibility of the primary oncologist. In recent years, the palliative care service has been more frequently consulted but this was not standard practice during the time period studied. Thus, many children likely enrolled in hospice through the care of a primary oncologist without ever meeting the palliative care team. For those children with palliative care consults, the service may have assisted with EOL symptom management for those children who died in the hospital, or participated in goals of care conversations for children who returned to the hospital after being enrolled in hospice. This could explain the negative correlation between palliative care consult and death at home in this cohort. Identifying the best time to involve a pediatric palliative care team in the care of children with cancer, and the outcomes impacted by such involvement, are other areas in need of future clinical investigation.

Limitations of this study are that this is a single-institution analysis of children with cancer. It may be difficult to generalize these results to children with other diagnoses, or to children with cancer who are treated in other institutions. The locations of death were not documented in the medical record or hospice database for 13 (14%) children eligible for hospice services, limiting our ability to draw firm conclusions about these children. It is possible that additional EOL discussions occurred in the patient home and were thus not documented in the medical record, and that physician documentation of EOL discussions in general was not complete. Other studies have described a lack of systematic documentation by physicians regarding patient preferences for EOL care and location of death; further investigation is required to establish how information may be adequately recorded, revised, and transferred across services to ensure that patient preferences are met.^{24,25} Strengths of this study are the high volume of patients treated in our institution and thus the high number of children who enrolled in hospice over the time period studied. A broad cross-section of racial and ethnic groups as well as socioeconomic mix is present as well, lending value to this first published description of the locations of death for children with cancer who are eligible for hospice, and hospice retention in those who enroll.

CONCLUSIONS

One quarter of those children with cancer who enrolled with an outpatient hospice service returned to the hospital and died in an acute care setting; 5 children died in the ICU. Death at home was not correlated with patient diagnosis, race/ethnicity, palliative care consult, or frequency of communication regarding EOL preferences. The median length of hospice services for children in this cohort was twice the national median observed in adults. Further studies are warranted to explore the hospice experience in children with cancer and to address modifiable factors that may impact the choice to withdraw from hospice care.

ACKNOWLEDGMENTS

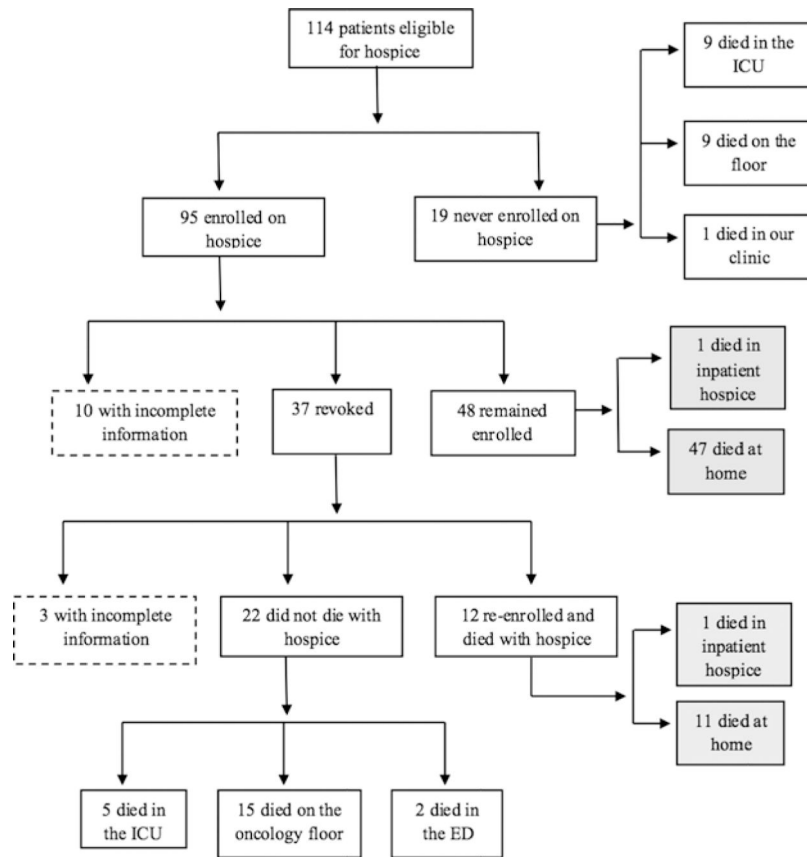
The authors wish to thank the Hospice of East Texas (Tyler, TX) and Community Hospice of Texas (Dallas, TX) for their help with acquisition of data from their respective organizations.

R.T. received 100% salary support for this project through a Fellows grant from the St. Baldrick's Foundation. S.C.L. receives some salary support from the UT Southwestern Center for Patient-Centered Outcomes Research (R24 HS022418).

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Abbreviations: ICU, intensive care unit; ER, emergency department.

FIGURE 1. Flow diagram of location of death for all patients eligible for hospice. ICU indicates intensive care unit; ED, emergency department.

TABLE 1.

Demographic Characteristics of Children Who Enrolled in Hospice

Characteristics	N (%)
Sex	
Male	48 (51)
Female	47 (49)
Race/ethnicity	
Hispanic	47 (49)
Non-Hispanic white	32 (34)
Other	16 (17)
Religion	
Catholic	26 (27)
Christian, NDS	17 (18)
Protestant	8 (8)
Other	7 (7)
NR/unknown	37 (39)
Payor status	
Medicaid	51 (54)
Private insurance/military	36 (38)
Private pay/CHSCN	7 (7)
Other	1 (1)
Diagnosis	
Brain tumors	37 (39)
Other solid tumors	34 (36)
Non-AML and lymphoma	17 (18)
AML	4 (4)
Other/BMT	3 (3)
DNR status	
Yes	43 (45)
No	41 (43)
Withdrawal of care	2 (2)
NR/unknown	9 (9)
Palliative care consult	
Yes	12 (13)
Number of EOL conversations	
0–2	55 (58)
3–14	40 (42)

AML indicates acute myelocytic leukemia; BMT, bone marrow transplant; CHSCN, children with special health care needs; DNR, Do-Not-Resuscitate; EOL, end of life; NDS, no denomination specified; NR, not recorded.

TABLE 2.

Average, Median, and Range of Time in Days From Diagnosis to Hospice Referral, Diagnosis to Hospice Enrollment, and Diagnosis to Death; Time From Hospice Referral and Hospice Enrollment to Death; and Time From DNR Order to Death

	Average (d)	Median (d)	Range (d)
Diagnosis to hospice enrollment	641	472	1–3170
Diagnosis to death	740	563	5–3998
Hospice enrollment to death	69	41	1–632
DNR order to death	29	15	0–242

DNR indicates Do-Not-Resuscitate.

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TABLE 3.Multiplied Adjusted χ^2 Statistics and *P*-Values for 2-Way Associations With Death at Home

Factors	χ^2	<i>P</i>
Race/ethnicity	1.5283	0.47
Religion	2.4508	0.29
Payor status	0.3699	0.54
Diagnosis	3.6062	0.16
Palliative care consult	0.2562	0.61
Number of EOL conversations	1.3071	0.25

EOL indicates end of life.

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