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End-of-Life Care Characteristics for Young Adults with Cancer Who Die in the Hospital

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Abstract

Background: Evidence suggests nonelderly adults with cancer are likely to receive aggressive treatment in their last month of life and less likely to receive hospice and/or palliative services. Young adults with cancer (18–39 years) are a unique population, and little is known about the characteristics of their end-of-life care trajectories when they die in the hospital.

Objective: The purpose of this descriptive pilot study was to explore the characteristics of death among young adults with cancer who died in a tertiary academic hospital in order to elucidate their end-of-life trajectories.

Methods: A retrospective chart review was conducted among hospitalized young adults with a primary cancer diagnosis who died in the hospital within a 10-year period. Study variables were abstracted for quantification and medical record notes were reviewed for validation.

Results: A review of 61 patient records indicate that young adults commonly received cancer treatment within weeks of death and that do-not-resuscitate orders were frequently written only when death appeared imminent. Palliative care teams were frequently consulted for management of physical symptoms but often within days of death and most commonly on the day of death.

Conclusions: Findings suggest palliative care was initiated late in the care trajectory for young adults with cancer who died in the hospital. This study highlights the need for further inquiry into end-of-life care for young adults with cancer so that interventions can be developed to meet the physical, emotional, social, and spiritual needs of this unique group of patients, their families, and friends.

Introduction

THE CURRENT FOCUS on young adult oncology is less than a decade old and highlights the burden of disease and risks of morbidity and mortality in young adults with cancer.[1,2] Caught between the worlds of pediatric and adult medical providers, young adults with cancer who are 18–39 years of age are less likely to access optimal medical and psychosocial services, compared to other age groups.[3] While the 5-year survival rates for some common young adult malignancies such as thyroid and testicular cancer exceed 80%, the survival rates for diseases such as leukemia remain less than 60%, with survival rates for some solid tumors even lower.[4]

An emerging trend in the literature suggests that nonelderly adults are more likely to receive aggressive treatment in the last month of their life (chemotherapy, intensive care unit [ICU] admission, cardiopulmonary resuscitation [CPR], intubation, and mechanical ventilation), but much of what we know is based on Medicare utilization in adults over 65.[5–10] Nonelderly adults are also less likely to receive palliative and/or hospice services prior to death.[6,11] From the pediatric perspective, the majority of children who die from cancer die in the initial treatment phase, in the hospital, in an ICU, while still receiving aggressive curative therapies (e.g., chemotherapy).[12–17] Preliminary evidence from adolescents at the end of life suggests that they prefer to die at home, yet the vast majority die in a hospital setting.[12] Furthermore, nearly 90% of children and adolescents who die from cancer do so while experiencing two to eight troubling symptoms.[18]

In general, little is known about the care trajectories of young adults with cancer as they near the end of life.[19] The purpose of this descriptive pilot study was to explore the characteristics of death among young adults with cancer who died in a tertiary academic hospital in order to elucidate the characteristics of end-of-life care specific to this age group. We also wanted to explore differences among characteristics of death between various diagnostic groups (hematologic malignancies, solid tumors, central nervous system [CNS] malignancies) as well as compare those patients who had an

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Table 1. Patient Characteristics, *n*=61

Characteristic n=*61*	*Number (%)*	*Mean (SD)*
Age at diagnosis		29.5 (6.5) Range 17–39
Age at death		30.7 (6.2) Range, 18–39
Gender		
Male	30 (49.2)	
Female	31 (50.8)	
Race		
White	48 (78.7)	
Black	11 (18.0)	
Other	2 (3.3)	
Marital status		
Single	33 (54.1)	
Married	24 (39.3)	
Other	4 (6.6)	
Disease type		
Hematologic	16 (26.2)	
Solid	32 (52.5)	
CNS	13 (21.3)	
Payer status		
Public coverage	19 (30.6)	
Private insurance	27 (43.5)	
Self-pay	9 (14.5)	
Other	5 (8.1)	
(missing)	1 (1.6)	
Relationship of hospital contact		
Parents	29 (47.5)	
Marital partner	22 (36.1)	
Sibling	5 (8.2)	
Other (friend/relative)	5 (8.2)	
Survival (months) diagnosis to death		15.2 (20.9) Range, 0.1–100
LOS (days)		15.1 (15.4) Range, 1–78
Advanced directives on file prior to admission		
None	56 (91.8)	
Yes	5 (8.2)	
Resuscitation status prior to admission		
Full code	53 (86.9)	
DNR	8 (13.1)	
New diagnosis during admission		
No	48 (78.7)	
Yes	13 (21.3)	
On active primary treatment for malignancy		
No	32 (52.5)	
Yes	29 (47.5)	
Documented goals of care discussion at admission		
No	41 (67.2)	
Yes	20 (32.8)	
Place of death		
Floor	39 (63.9)	
ICU	22 (36.1)	
Cause of death		
Disease-related	51 (83.9)	
Complication-related (e.g., sepsis)	10 (16.4)	
ICU stay		
No	32 (52.5)	
Yes	29 (47.5)	
ICU LOS (days)		13.9 (16.4) Range, 1–78
CPR performed		
No	50 (82.0)	
Yes	11 (18.0)	
Palliative care consult		
No	31 (50.8)	
Yes	30 (49.2)	
Palliative care consult more than 1 day prior to death (of those with palliative care consult *n*=30)		
No	11 (36.7)	
Yes	19 (63.3)	
Timing of palliative care consult (days prior to death)		12.8 (25.1) Range, 0–120
DNR order prior to death		
No	7 (11.5)	
Yes	54 (88.5)	
Timing of DNR order (days prior to death)		9.8 (23.8) Range, (1–60)
Documentation of family meeting		
No	14 (23.0)	
Yes	47 (77.0)	
Hospital cost		$85,578.42 (95,156.66) Range, ($2850.00–371,726.00)

SD, standard deviation; CNS, central nervous system; LOS, length of stay; DNR, do-not-resuscitate; ICU, intensive care unit; CPR, cardiopulmonary resuscitation.

ICU admission preceding their death with those who did not have an ICU admission. To the authors' knowledge, characteristics of care trajectories among young adults who die of cancer have not been previously described.

Materials and Methods

Study design and subject overview

This retrospective study received Institutional Review Board exemption prior to study initiation. The University of Virginia's Clinical Data Repository (CDR) was used for subject identification based on a single query. Patients were identified using: death between ages 18–39, primary diagnosis of cancer of any origin (based on malignant neoplasm *ICD-9* codes), who died while admitted to the hospital within a 10-year span (2001–2011). Therefore, all patients who met inclusion criteria were included in this study. Once patients were identified, a retrospective chart review was conducted, and a set of objective variables were abstracted using the electronic medical record and CDR. Annotated notes were reviewed to confirm and validate variables of interest that included analysis of: discharge summaries (which described death), progress notes, nursing notes,

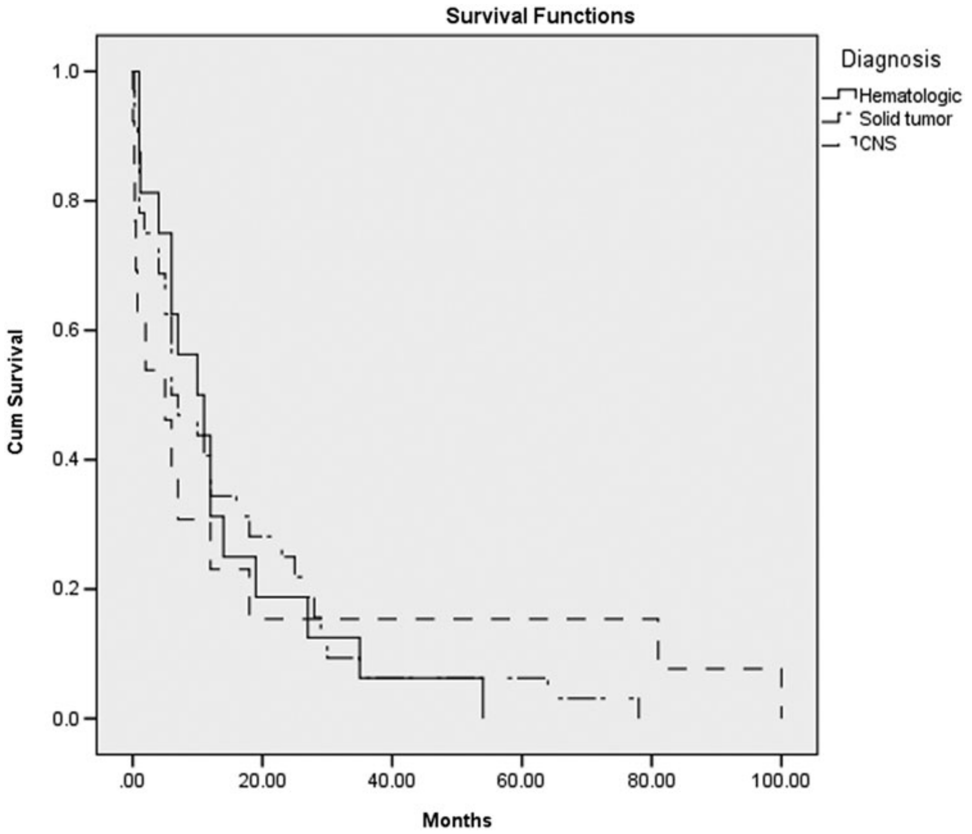

FIG. 1. Kaplan-Meier survival curve by disease type (survival since diagnosis; $p = 0.994$).

procedure notes, social work consults, palliative care consults, and other specialty consult notes. The final admission preceding the death was the admission of primary focus for this study, but all notes following diagnosis were reviewed to determine palliative care involvement. Several variables including cost, charges, and insurance status were supplemented from the CDR.

Variables included demographic characteristics (age, race, gender), payer status, primary cancer diagnosis (hematologic malignancy, solid tumor, brain/CNS tumor), place of death

Table 2. Characteristics by Disease Type (Mean or Percentage)

Characteristic	*Hematologic* (n = *16*)	*Solid tumor* (n = *32*)	*CNS* (n = *13*)	p *value*
Age at diagnosis	27.44	31.31	27.54	0.110
Age at death	28.75	32.28	29.08	0.105
Survival (months)	13.73	14.79	17.92	0.862
LOS (days)	22.69	13.75	9.08	0.044[a]
New diagnosis at admission	18.75% (3/16)	15.63% (5/32)	38.46% (5/13)	0.38
Advanced directives at admission	6.25% (1/16)	9.38% (3/32)	7.69 (1/13)	0.93
DNR at admission	6.25% (1/16)	15.63% (5/32)	15.38% (2/13)	0.64
Active primary therapy	62.5% (10/16)	53.12% (17/32)	15.38% (2/13)	0.027[a]
Goals of care discussion at admission	12.5% (2/16)	34.38% (11/32)	53.85% (7/13)	0.06
ICU as place of death	56.25% (9/16)	21.88% (7/32)	46.15% (6/13)	0.045[a]
ICU LOS (days)	11.92	20.69	10.25	0.396
CPR used	18.75% (3/16)	15.63% (5/32)	23.08% (3/13)	0.837
Palliative care consult received	25% (4/16)	65.63% (21/32)	38.46% (5/13)	0.02[a]
Timing of palliative care consult before death (days)	2.60	17.33	3.80	0.351
DNR order prior to death	93.75% (15/16)	87.5% (28/32)	84.61%(11/13)	0.719
Timing of DNR order prior to death (days)	3.87	5.50	2.55	0.668
Hospital cost	$140,170.27	$71,677.94	$55,724.77	0.029[a]

[a] Denotes significance at 0.05 level.

LOS, length of stay; DNR, do-not-resuscitate; ICU, intensive care unit; CPR, cardiopulmonary resuscitation.

Table 3. Characteristics by ICU Stay Status (Mean or Percentage)

Characteristic	*ICU stay* (n = *29*)	*No ICU stay* (n = *32*)	p *value*
Age at diagnosis (years)	27.90	30.94	0.444
Age at death (years)	28.86	32.31	0.493
Survival (months)	11.45	18.57	0.309
LOS (days)	19.10	11.47	0.038[a]
New diagnosis at admission	37.93% (11/29)	6.25% (2/32)	0.003[a]
Advanced directives at admission	0 (0/29)	15.63% (5/32)	0.026[a]
DNR at admission	0 (0/29)	25% (8/32)	0.004[a]
Active primary therapy	43.75% (14/29)	46.88% (15/32)	0.913
Goals of care discussion at admission	17.24% (5/29)	46.88% (15/32)	0.014[a]
CPR used	31.03% (9/29)	6.25% (2/32)	0.012[a]
Palliative care consult received	31.03% (9/29)	65.63% (21/32)	0.007[a]
Timing of palliative care consult before death (days)	4.20	16.86	0.038[a]
DNR status prior to death	82.76% (24/29)	93.75% (30/32)	0.179
Timing of DNR prior to death (days)	2.33	6.13	0.086
Hospital cost	$132,763.82	$42,959.35	0.023[a]

[a] Denotes significance at 0.05 level.

ICU, intensive care unit; LOS, length of stay; DNR, do-not-resuscitate; CPR, cardiopulmonary resuscitation.

(acute care floor, ICU, emergency department), resuscitation status, cause of death, overall length of stay (LOS), ICU LOS, current active therapy (i.e., chemotherapy administration or radiation therapy 4 weeks prior to death), presence of advance directives (AD), CPR performed, palliative care consult, and documentation of family meeting.

Analysis

Descriptive statistics were calculated to describe all variables using mean/standard deviation for continuous variables and frequency/percentage for categorical variables. Significant differences in pertinent outcome variables were compared among diagnostic groups (hematologic malignancy, solid tumor, brain/CNS) and compared among those patients who had an ICU stay versus no ICU stay using either *t* tests for continuous variables with normal distributions and the χ^2 statistic (and Fisher's exact test when $n < 10$) for dichotomous variables. Kaplan-Meier survival curves were calculated to compare the three diagnostic classifications on their survival since diagnosis. During initial data abstraction, it was hypothesized that there may be significant differences among those patients who had palliative care consult more than 1 day prior to death compared to those who either had no palliative care consult, or a palliative care consult on the day of death for withdrawal of life-sustaining interventions. Therefore, this *post hoc* comparison was also performed using *t* tests and χ^2/Fisher's exact tests. Finally, independent associations between palliative care consult more than 1 day and outcome variables were calculated. Odds ratios and confidence intervals were calculated to determine the impact of palliative care consult more than 1 day on patient-related outcomes. Statistics were calculated with SPSS version 20, (IBM SPSS, Armonk, NY).

Table 4. Characteristics by Receiving Palliative Care Consult More Than One day (Mean or Percentage)

Characteristic	*Palliative care consult > 1 day before death* (n = *19*)	*No palliative care consult/palliative care consult on day of death* (n = *42*)	p *value*
Age at diagnosis	31.32	28.67	0.346
Age at death	33.11	29.57	0.288
Survival (months)	20.02	12.99	0.019[a]
LOS	14.37	15.43	0.121
New diagnosis at admission	21.05 (4/19)	21.42 (9/42)	0.974
Advanced directives at admission	15.79 (3/19)	4.76 (2/42)	0.146
DNR at admission	21.05 (4/19)	9.52 (4/42)	0.217
Active primary therapy	47.37 (9/19)	47.62 (20/42)	0.986
Goals of care discussion at admission	42.11 (8/19)	28.57 (12/42)	0.297
ICU as place of death	10.53 (2/19)	47.62 (20/42)	0.005[a]
ICU LOS	15.25	13.64	0.979
CPR used	15.79 (3/19)	19.05 (8/42)	0.759
Documentation of family meeting	94.73 (18/19)	69.05 (8/42)	0.036[a]
DNR order prior to death	89.47 (17/19)	88.10 (37/42)	0.876
Timing of DNR order prior to death (days)	9.94	1.92	0.001[a]
Hospital cost	$81,373.47	$87,575.30	0.925

[a] Denotes significance at 0.05 level.

LOS, length of stay; DNR, do-not-resuscitate; ICU, intensive care unit; CPR, cardiopulmonary resuscitation.

Results

A total of 61 patients met inclusion criteria for this study. These young adults had a mean age of 30 years and an average survival of 15.2 months from time of diagnosis to death. The majority of patients had a solid tumor (51.6%), were single (53%), and white (77%). Only 8.2% had an AD upon admission, and 13.1 had a do-not-resuscitate (DNR) order documented prior to the admission. Thirteen patients (21%) were diagnosed with cancer during this same admission as their death. The remaining patient characteristics can be found in Table 1.

The Kaplan-Meier survival curve by disease type (Fig. 1) showed no significant difference in survival between those with a hematologic malignancy, solid tumor, or brain tumor/ CNS disease. However, significant differences in care were found between diagnostic groups (Table 2). Those with hematologic malignancies had longer LOS (22.7 days versus 13.8 for solid tumor and 9.1 for CNS, $p = 0.044$), were more likely to die in the ICU (56% versus 22% for solid tumor and 46% CNS, $p = 0.045$), and had more costly hospitalization on the final admission ($140,000 versus $72,000 for solid tumor, $56,000 for CNS, $p = 0.029$). Those with solid tumors were more likely to receive palliative care consults (66% versus 25% for hematologic and 38% CNS, $p = 0.02$).

When comparisons were made between patients who had an ICU stay during the final admission and patients with no ICU stay, patients who had an ICU stay had significantly longer (19.1 days versus 11.5 days, $p = 0.038$) and more expensive hospitalizations ($133,000 versus $43,000, $p = 0.023$). Patients who did not have an ICU stay were significantly more likely to have documented AD (16% versus 0, $p = 0.026$), a discussion about goals of care at admission (47% versus 17%, $p = 0.014$), to have a palliative care consult (66% versus 31%, $p = 0.007$), and to have the palliative care consult earlier (16.9 versus 4.2 days, $p = 0.038$; Table 3).

Finally, patients who had palliative care consults more than 1 day before they died were significantly less likely to die in the ICU (11% versus 48%, $p = 0.005$), more likely to have documentation of a family meeting (95% versus 69%, $p = 0.036$), have DNR orders documented days prior to their death (9.9 days versus 1.9, $p = 0.001$), and exhibit a longer overall survival (20 months versus 13, $p = 0.019$; Table 4). When odds ratios were calculated, those with no palliative care consult/palliative care consult received on the day of death were nearly three times as likely to have an ICU stay during the admission of death compared to those who received a palliative care consult more than 1 day prior to death (odds ratio 2.83, confidence interval 1.143–6.994).

Discussion

This study provides preliminary evidence demonstrating opportunities that exist for early goal-directed discussions after a young adult is diagnosed with cancer. Findings from this descriptive pilot data are hypothesis-generating because they highlight differences in care outcomes between those who receive early palliative care. In our review, those with palliative care consults more than 1 day prior to death exhibited significantly longer overall survival, greater occurrence of documentation of family meetings, DNR orders written more days prior to death, and less occurrence of death in the ICU. Only half of this study population received a palliative care consult prior to death. Our data suggests that a palliative care consult was often initiated on the day of death to help the primary team transition the dying patient to comfort measures. More research is needed to understand the barriers of earlier palliative care involvement among this unique population while also elucidating the reason for palliative care consult (e.g., transition to comfort measures versus comprehensive symptom management). The earlier use of palliative care would have great utility in providing symptom-based, psychosocial and spiritual support in this unique population.[20]

These data are limited because it is a single academic center, with a small sample size, included all cancer types, and relied solely on what was available through retrospective chart review so it lacks generalizability. Additionally, the sample itself was limited because it did not include those who died in their homes or in hospice care settings. Even so, this study provides preliminary descriptive evidence highlighting the care trajectories and progression in acute care and ICU settings of young adults with cancer who died in the hospital. Larger prospective studies are needed to further investigate end-of-life care needs among young adults with cancer.

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