

High Intensity of End-of-Life Care Among Adolescent and Young Adult Cancer Patients in the New York State Medicaid Program

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Background: Little is known about the care that adolescent and young adult (AYA) cancer patients receive at the end of life (EOL).

Objective: To evaluate use of intensive measures and hospice and location of death of AYA cancer patients insured by Medicaid in New York State.

Design: Using linked patient-level data from the New York State Cancer Registry and state Medicaid program, we identified 705 Medicaid patients who were diagnosed with cancer between the ages of 15 and 29 in the years 2004–2011, who subsequently died, and who were continuously enrolled in Medicaid in the last 60 days of life. We evaluated use of intensive EOL measures (chemotherapy within 14 d of death; intensive care unit care, >1 emergency room visit, and hospitalizations in the last 30 d of life), hospice use, and location of death (inpatient hospice, long-term care facility, acute care facility, home with hospice, home without hospice).

Results: 75% of AYA Medicaid decedents used at least 1 aspect of intensive EOL care. 38% received chemotherapy in the last 2 weeks of life; 21% received intensive care unit care, 44% had >1 emergency room visit, and 64% were hospitalized in the last month of life. Only 23% used hospice. 65% of patients died in acute care settings, including the inpatient hospital or emergency room.

Conclusions: Given the high rates of intensive measures and low utilization of hospice at the EOL among AYA Medicaid enrollees, opportunities to maximize the quality of EOL care in this high-risk group should be prioritized.

Key Words: cancer, end of life, Medicaid, adolescent/young adult, hospice

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Cancer is the leading illness-related cause of death among adolescents and young adults (AYAs) in the United States.¹ Comprehensive attention to medical and psychosocial needs at the end of life (EOL) is considered a fundamental aspect of quality cancer care for the AYA population.^{2–6} Previous work has focused on treatment decision making,⁷ psychosocial distress,^{8–10} and the development of advance care planning tools in this population,^{11,12} but little is known about the care that AYA cancer patients receive at the EOL. As a result, 2013 Institute of Medicine Workshop has called for increased research into EOL care for AYAs.¹³

Efforts to optimize EOL care depend on a better understanding of the care that young people receive, including the intensity of care at the EOL, the extent to which AYA patients utilize hospice care, and where they die. These issues offer insight into EOL care quality for several reasons. First, most patients who recognize that they are terminally ill prefer not to receive aggressive measures at the EOL,¹⁴ but instead prefer care focused on controlling symptoms and maximizing quality of life; thus, understanding the prevalence of aggressive EOL measures provides a window into how well patients are able to plan for death. In addition, patients who receive intensive EOL care experience poorer quality of life at the EOL.^{15,16} Aggressive EOL care is also associated with poorer bereavement outcomes among family members, and thus affects the patient's entire family beyond death.¹⁶ Finally, intensive EOL care is also more costly than palliative care.^{17–19} Thus, multiple lines of evidence suggest that intensive EOL care can have negative effects on individuals and the health care system. Understanding rates of intensive EOL care among AYA cancer patients can provide insight about patterns of care and identify gaps in palliative care delivery in this young population.

Tumor registry data linked to administrative claims are an important tool to characterize patterns of cancer care, particularly in the Medicare population. For the AYA population, there is no single insurer; however, many AYAs are

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insured by Medicaid programs. The New York State Medicaid Program insures >6 million New Yorkers with low incomes and resources, providing inpatient, outpatient, and home health services, including hospice, as well as prescription drugs; eligibility is determined by income, household size, and disability. In addition, many AYAs have no insurance at the time of a cancer diagnosis and/or lose the ability to work and, therefore, become Medicaid eligible. A cancer diagnosis is also a qualifying event for Medicaid in many states including New York.

To more fully understand the EOL care received by AYA cancer patients, we evaluated EOL care among Medicaid insured patients aged 15–29 in New York who were diagnosed with cancer between 2004 and 2011, the most recent years for which data were available. The AYA age range has been variously defined, and some groups, including the National Cancer Institute, include patients up to age 39. However, patients in their 30s often have completed their education and established careers and families, unlike those in the younger age range; given marked differences in social, educational, and family trajectories across the wider age range, we chose to limit our population to those in the 15–29 age group.²⁰

Patients were eligible if they were enrolled in Medicaid in the peridiagnosis period, defined as 6 months before diagnosis through 6 months subsequent to diagnosis, and remained continuously enrolled in Medicaid in the 60 days before death, such that EOL care indicators were evaluable. The choice of peridiagnosis enrollment allowed us to focus on patients who were likely to have received cancer care within Medicaid, and eliminate those who may have been temporarily enrolled years earlier. Linked cancer registry and administrative data allowed us to evaluate measures of EOL care intensity,^{21,22} including use of chemotherapy, hospitalizations, emergency room (ER) visits, and intensive care unit (ICU) admissions at the end of life; hospice use, type, and duration; and location of death.

METHODS

This study utilized linkages between the New York State Cancer Registry (NYSCR) and Medicaid files. NYSCR is part of the CDC’s National Program of Cancer Registries and has consistently achieved the highest certification from the NAACCR.²³ Linkages allowed for assessment of cancer stage and vital status from the tumor registry, and enrollment and health care utilization from Medicaid administrative data. Methods for creation of the NYSCR-Medicaid linkage have been previously reported.²⁴ Patients with incident cancer diagnoses from 2004 to 2011 were linked to Medicaid enrollment, eligibility, encounter, and claims files by a probabilistic matching algorithm using social security numbers, first, middle and last names, date of birth, and sex. Data were further linked to the state hospital discharge file (Statewide Planning and Research Cooperative System), which includes detail on patient characteristics, diagnoses, treatments, services, and source of payment for all inpatient hospital discharges. The tumor registry merged, deidentified, and encrypted data. The project was approved by IRBs at

DFCI and the New York State Department of Health, and data were analyzed in accordance with the New York Department of Health’s data use agreement.

Cohort Definition

We first identified New York state patients aged 15–29 at diagnosis with any stage cancer of any pathologic subtype in the years 2004–2011, and excluded patients in hospice before diagnosis or with postmortem diagnoses (Fig. 1). Medicaid enrollment was tracked for each month from 6 months before diagnosis until the month of death or the date of censoring (December 31, 2011), and the cohort was restricted to patients who were insured by Medicaid in the peridiagnosis period, defined as Medicaid enrollment at any time from 6 months before diagnosis through 6 months after diagnosis (74%, 4889/6589 of patients ever enrolled in Medicaid). Patients with in situ cancers or unknown stage were excluded. Stage I–III cancers and stage IV cancers were evaluated separately given the relatively better prognoses of stage I–III cancers and the potential that such patients would

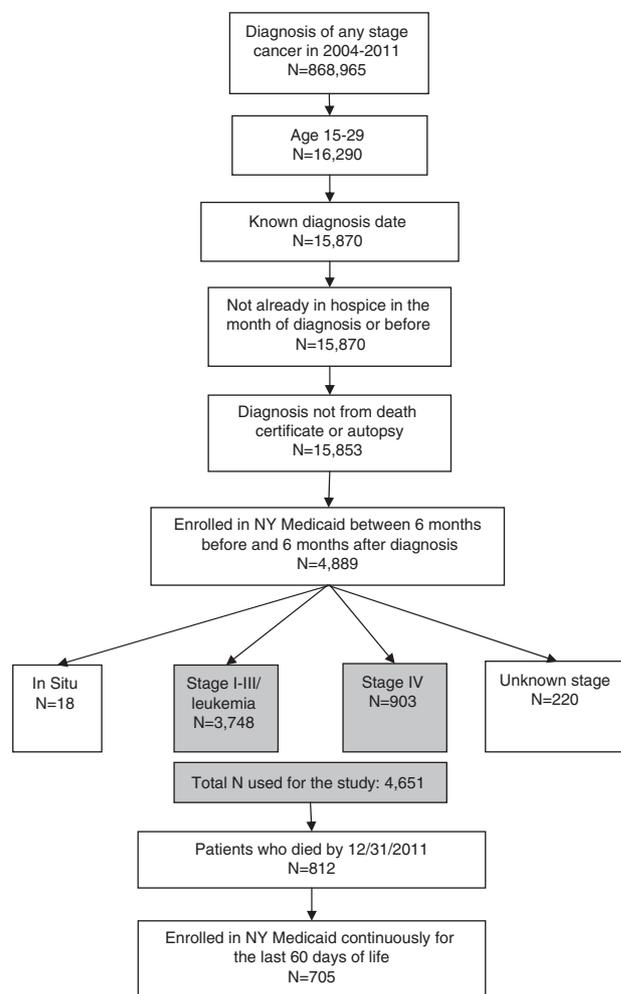


FIGURE 1. Cohort formation flow diagram. Sample sizes refer to the number of patients included in the cohort at each phase.

approach EOL care differently; leukemias were included with stage I–III cancers for similar reasons. The resulting cohort included 4651 patients, 3748 of whom had stage I–III cancers or leukemia, and 903 of whom had stage IV cancer at diagnosis. Patients insured by NY Medicaid in the peridiagnosis period represented 37% of all AYA cancer patients diagnosed in New York State between 2004 and 2011 (4651/12,590). In total, 814 AYA Medicaid patients died within the data review period; 705 were continuously enrolled in the last 60 days of life (425 patients with stage I–III cancer or leukemia, and 280 with stage IV cancer) and constituted the primary cohort for analysis of EOL care measures.

We captured information about cancer diagnoses, including site, histology, stage (SEER summary stage; AJCC stage used when SEER summary stage was not available), and vital status, from the NYSCR. We obtained information about care at the EOL from administrative data reported by the NYS Medicaid program. The NYS Medicaid program requires submission of itemized encounter data even for beneficiaries enrolled in managed care plans. For this reason, NYS Medicaid administrative data can be used to ascertain patterns of care.

Individuals' eligibility for Medicaid can fluctuate over time as employment, disability, and income change. We used NYS Medicaid records to identify month-specific Medicaid enrollment for each AYA in NYS. After categorizing patients as initially covered or not covered by Medicaid within the 12-month peridiagnosis period, we then categorized patients according to the continuity of enrollment in NY Medicaid. Patients were either continuously enrolled in Medicaid (from diagnosis until death or censoring), enrolled for $\geq 50\%$ of the months between diagnosis and death/censoring, or enrolled for $<50\%$ of the months between diagnosis and death/censoring.

EOL Care Intensity Measures

Measures of EOL care intensity were adapted from those developed by Earle et al,^{21,22,25} including chemotherapy use within 14 days of death, care in the ICU within 30 days of death, >1 ER visit within 30 days of death, and hospitalization within 30 days of death. We also included a composite measure comprising any of the above intensive EOL care measures. All measures were anchored to date of death according to tumor registry data, with date of service used to determine whether the event fell into the relevant window. Chemotherapy use was evaluated using a combination of pharmacy and type of service codes previously developed for use in New York Medicaid files.²⁶ ICU care was evaluated using revenue codes indicating intensive care. ER visits were measured using established category of service or provider place of service codes; hospitalizations were identified using category of service codes.

Hospice Use and Location of Death

Hospice use was established by the presence of any hospice encounter or claim for services in any hospice file. The date of first hospice claim/encounter was considered the date of enrollment, which was used to evaluate days from

diagnosis (based on registry diagnosis date) to enrollment, and length of stay in hospice from enrollment until death or censoring.

We categorized the setting of hospice care delivery as home hospice, inpatient hospice in a hospice facility, inpatient hospice within a long-term care or skilled nursing facility, or both inpatient and home hospice. Hospice type was identified using a combination of rate and place of service codes defined by the New York State Department of Health.²⁷ Hospice claims lacking inpatient hospice criteria were considered home hospice.

We evaluated location of death using place of service codes on all claims from the death date, including care in an inpatient hospice facility, long-term care facility/skilled nursing facility, or acute care facility (inpatient hospital or ER). Patients enrolled in hospice before death, but lacking inpatient place of service codes on the death date, were categorized as dying in home hospice irrespective of the last home visit date. The location of death was considered to be home without hospice if no inpatient claims were recorded on the date of death and the patient was never enrolled in hospice.

Patient Characteristics

For each patient, we evaluated sex, age, race, ethnicity, marital status, and date of diagnosis. Comorbidity, expressed as Charlson score,²⁸ was estimated using the Klabunde method²⁹ using inpatient and outpatient claims, modified for cancer diagnosis; patients who did not have 13 months of claims antecedent to diagnosis were evaluated separately. The median income for zip code of residence was evaluated using zip code income data for the year 2010.

Analysis

We evaluated patient-level differences in use of intensive EOL care measures and hospice, first comparing patients by patient characteristics within stage category and then between stage category, using Fisher's exact test for 2-category comparisons and χ^2 tests for multicategory comparisons. Differences in distributions of continuous variables were compared using Wilcoxon 2-sample tests.

Factors associated with use of any intensive EOL care measures, and factors associated with hospice use, were evaluated using logistic regression. Separate models were constructed for each outcome. Multivariable analyses included patient race, ethnicity, sex, age at diagnosis, marital status, median income for zip code of residence, comorbidity, year of diagnosis, diagnosis, continuity of enrollment, basis of eligibility for Medicaid, and region, regardless of significance. Models were first constructed separately by stage category (stage I–III cancer or leukemia vs. stage IV, data not shown) and then, given the lack of major differences, as combined models adjusted for stage category. All analyses were performed using SAS, version 9.2 (SAS Institute, Cary, NC).

RESULTS

Of 4651 AYA Medicaid patients diagnosed in New York state between 2004 and 2011, 705 (15%) died within

TABLE 1. Characteristics of AYA Cancer Patients (N=4651) Who Received Care in New York Medicaid, 2004–2011

	NY Medicaid Patients Diagnosed With Stage I-III Cancer or Leukemia [n (%)]		NY Medicaid Patients Diagnosed With Stage IV Cancer [n (%)]	
	All Patients	Decedents (Cohort Patients Who Died During the Data Period, Before December 31, 2011)	All Patients	Decedents (Cohort Patients Who Died During the Data Period, Before December 31, 2011)
N	3748	426	903	280
Race				
White	2510 (67)	276 (65)	565 (63)	171 (61)
Black	763 (20)	111 (26)	256 (28)	89 (32)
Asian/other	475 (13)	38 (9)	82 (9)	20 (7)
Ethnicity				
Hispanic	1009 (27)	120 (28)	260 (29)	81 (29)
Non-Hispanic	2739 (73)	305 (72)	643 (71)	199 (71)
Age at diagnosis (y)				
15–21	1122 (30)	149 (35)	290 (32)	88 (31)
22–29	2626 (70)	276 (65)	613 (68)	192 (69)
Sex				
Female	2046 (55)	168 (40)	380 (42)	129 (46)
Male	1701 (45)	257 (60)	522 (58)	151 (54)
Marital status				
Married	608 (16)	52 (12)	98 (11)	25 (9)
Single/widowed/unknown	3140 (84)	373 (88)	805 (89)	255 (91)
Median income for zip code of residence				
Lowest quartile	1724 (46)	191 (45)	441 (49)	143 (51)
2nd quartile	1010 (27)	120 (28)	223 (25)	57 (20)
3rd quartile	692 (18)	68 (16)	150 (17)	53 (19)
Highest quartile	321 (9)	46 (11)	89 (10)	27 (10)
Comorbidity estimate*				
< 13 mo of claims	446 (12)	53 (12)	136 (15)	38 (13)
0–1	3204 (85)	346 (82)	721 (80)	220 (79)
≥ 2	98 (3)	26 (6)	46 (5)	22 (8)
Year of diagnosis				
2004–2007	1733 (46)	276 (65)	432 (48)	166 (59)
2008–2011	2015 (54)	149 (35)	471 (52)	114 (41)
Diagnosis				
Hodgkin lymphoma	336 (9)	17 (4)	245	26
Non-Hodgkin lymphoma	201 (5)	27 (6)	175	65
Leukemia	597 (16)	147 (35)	0 (0)	0 (0)
Bone/joint/soft tissue	219 (6)	39 (9)	75 (8)	42 (15)
Testicular or gynecologic	612 (16)	33 (8)	150 (17)	29 (10)
Colorectal	115 (3)	20 (5)	54 (6)	28 (10)
Central nervous system	314 (8)	55 (13)	†	†
Breast	196 (5)	18 (4)	†	†
Other	1667 (44)	142 (33)	204 (23)	90 (32)
Enrolled in Medicaid at diagnosis	3085 (82)	364 (86)	730 (81)	233 (83)
Continuity of enrollment‡				
Continuous	1651 (44)	268 (63)	417 (46)	194 (69)
> 50% enrollment	1152 (31)	137 (32)	279 (31)	64 (23)
< 50% enrollment	945 (25)	20 (5)	207 (23)	22 (8)
Geographic region§				
Very large metropolitan	2081 (56)	250 (59)	527 (58)	166 (59)
Large urban/suburbs	461 (12)	53 (12)	120 (13)	41 (15)
Urban	568 (15)	55 (13)	128 (14)	40 (14)

(Continued)

TABLE 1. Characteristics of AYA Cancer Patients (N=4651) Who Received Care in New York Medicaid, 2004–2011 (continued)

	NY Medicaid Patients Diagnosed With Stage I–III Cancer or Leukemia [n (%)]		NY Medicaid Patients Diagnosed With Stage IV Cancer [n (%)]	
	All Patients	Decedents (Cohort Patients Who Died During the Data Period, Before December 31, 2011)	All Patients	Decedents (Cohort Patients Who Died During the Data Period, Before December 31, 2011)
Rural/not urban	637 (17)	67 (16)	128 (14)	33 (12)
Vital status				
Died within 2 y of diagnosis	324 (9)	293 (69)	264 (29)	232 (83)
Basis of eligibility for Medicaid				
Poverty	3028 (81)	306 (72)	666 (74)	203 (73)
Disabled/unknown	720 (19)	119 (28)	237 (26)	77 (27)

*Charlson score estimated by the Klabunde method using inpatient and outpatient claims, modified for cancer diagnosis. Score not calculated for patients who without 13 continuous months of claims antecedent to diagnosis.

†Small cell sizes of 10 or fewer have been masked, along with 1 additional cell when numbers could be derived from existing data.

‡Continuity of enrollment categories: Continuously enrolled between the month of diagnosis and the month of death or censoring; enrolled >50% of the time, but not continuously, between the month of diagnosis and the month of death or censoring; enrolled <50% of the time between the month of diagnosis and the month of death or censoring.

§Region was defined as very large metropolitan (New York City), large urban/suburbs (the surrounding New York City suburbs), urban (counties with cities of 100,000–300,000 residents), and rural/not urban (counties with towns <100,000).

the study period and were continuously enrolled in the last 60 days of life, including 11% of those diagnosed with stage I–III cancer or leukemia (426/3748), and 31% (280/903) of those diagnosed with stage IV cancer (Table 1). Most decedents died within 2 years of diagnosis (69% stage I–III/leukemia, 83% stage IV.)

Black (26% stage I–III/leukemia, 32% stage IV) and Hispanic (28% stage I–III/leukemia, 29% stage IV) patients comprised a substantial proportion of the decedent cohort, in similar proportions to the full AYA Medicaid population. Most patients (63% stage I–III/leukemia, 69% stage IV) were enrolled continuously between diagnosis and death or censoring, and a majority were eligible for Medicaid on the basis of poverty (72% stage I–III/leukemia, 73% stage IV). In the full AYA Medicaid cohort, no major sociodemographic differences were found between patients enrolled in Medicaid before the Affordable Care Act (ACA) began offering the opportunity for young people through age 26 to remain insured by their parents in September 2010, versus those enrolled post-ACA, with the exception of fewer enrollments on the basis of poverty post-ACA (74% vs. 81%, $P < 0.001$). In the decedent cohort, only 37 patients were diagnosed post-ACA.

New York AYA patients without Medicaid were more likely than those in Medicaid to be white (81%), non-Hispanic (89%), female (58%), married (19%), and in higher income zip codes ($P < 0.001$ for all). The non-Medicaid cohort also had fewer patients with leukemia (5%) and lymphoma (14%, $P < 0.001$ across all diagnosis categories).

Three quarters of all AYA Medicaid decedents received at least 1 intensive measure at the EOL (75%, 529/705) (Table 2). More than one third of patients received chemotherapy in the last 2 weeks of life (38%). In the last month of life, 21% of patients received ICU care, 44% had >1 ER visit, and 64% were hospitalized. When intensive EOL measures were evaluated among 469 patients continuously enrolled in Medicaid between diagnosis and death or censoring, 82% used at least 1 intensive measure (N = 381, $P < 0.0001$ relative to those without continuous enrollment).

Only 23% of patients were in hospice care before death, with first enrollment a median of 20 days (range, 8–45) before death. Outpatient hospice was the predominant model of hospice care delivery, used by 81% of patients in hospice, and 19% of all decedents died at home with hospice in place. Most patients (65%) died in acute care settings, including inpatient hospitals and the ER; a minority died at home without hospice (11%), in an inpatient hospice (3%), or in a long-term care facility (2%).

In multivariable models adjusted for patient attributes, older patients [adjusted odds ratio (AOR), 1.59 for age 22–29; 95% confidence interval (CI), 1.08–2.35; $P = 0.02$; relative to age 15–21, Table 3] and patients with stage IV disease at diagnosis (AOR, 1.58; 95% CI, 1.03–2.43; $P = 0.04$) had increased odds of receiving intensive EOL care measures. Use of intensive measures also varied by continuity of enrollment in Medicaid ($P < 0.0001$).

In adjusted models, hospice utilization was higher among patients who were younger (AOR, 0.60 for age 22–29; 95% CI, 0.40–0.91; $P = 0.02$; relative to age 15–21), married (AOR, 0.52 for unmarried status relative to married; 95% CI, 0.29–0.98; $P = 0.04$), and diagnosed with lower stage disease (AOR, 0.56; 95% CI, 0.37–0.86; $P < 0.01$; for stage IV relative to stage I–III disease and leukemia). In addition, diagnosis was associated with hospice use ($P < 0.0001$), with leukemia patients enrolling in hospice at lower rates (AOR, 0.42; 95% CI, 0.19–0.95) than those with lymphoma, and higher enrollment relative to lymphoma among patients with bone, joint, and soft tissue cancers (AOR, 3.16; 95% CI, 1.50–6.75), testicular or gynecologic cancers (AOR, 2.58; 95% CI, 1.15–5.80), colorectal cancer (AOR, 7.50; 95% CI, 3.34–17.31), and all other cancer types (AOR, 2.37; 95% CI, 1.30–4.49).

DISCUSSION

Although there is no accepted ideal rate of use of intensive measures and hospice at the EOL, the AYA Medicaid decedents we studied used more intensive measures than have

TABLE 2. Use of Intensive EOL Care and Hospice Among Adolescent and Young Adult Cancer Patients in NY Medicaid

	NY Medicaid Decedents Diagnosed With Stage I-III Cancer or Leukemia N=425	NY Medicaid Decedents Diagnosed With Stage IV Cancer N=280	All NY Medicaid Decedents N=705
End-of-life intensity measures [n (%)]			
Chemotherapy within 14 d of death	155 (36)	114 (41)	269 (38)
Care in the ICU within 30 d of death	81 (19)	66 (24)	147 (21)
> 1 ER visit within 30 d of death	185 (44)	122 (44)	307 (44)
Hospitalized within 30 d of death*	252 (59)	199 (71)	451 (64)
Any of the above intensive EOL measures	308 (72)	221 (79)	529 (75)
Ever in hospice [n (%)]	101 (24)	60 (21)	161 (23)
	Patients in Hospice (N=101)	Patients in Hospice (N=60)	Patients in Hospice (N=161)
Days from diagnosis to 1st hospice enrollment			
Mean (SD)	706 (528)	461 (373)	615 (489)
Median (IQR)**	575 (373–837)	318 (240–598)	493 (267–761)
Days in hospice from entry until death or censoring			
Mean	51 (78)	25 (33)	41 (66)
Median IQR**	24 (12–55)	14 (5–33)	20 (8–45)
Type of hospice used [n (%)]			
Inpatient hospice or hospice within SNF only	19 (19)	8 (13)	27 (17)
Outpatient hospice only	78 (77)	52 (87)	130 (81)
Both inpatient and outpatient hospice	4 (4)	0 (0)	4 (2)
Location of death [n (%)]	N=425	N=280	N=705
Home without hospice	41 (10)	34 (12)	75 (11)
Home with hospice	83 (19)	51 (18)	134 (19)
Inpatient hospice	16 (4)	7 (3)	23 (3)
Long-term care facility/SNF	7 (2)	8 (3)	15 (2)
Acute care (inpatient or emergency room)	278 (65)	180 (64)	458 (65)

EOL indicates end of life; ICU, intensive care unit; SNF, skilled nursing facility.
 * $P < 0.05$ by χ^2 test comparing stage I-III cancer/leukemia to stage IV cancer patients.
 ** $P < 0.05$ by Wilcoxon 2-sample test comparing stage I-III cancer/leukemia to stage IV cancer patients.

been historically seen among their older adult counterparts in Medicare, with little home support from hospice. Earle et al²¹ previously reported, for example, that fewer than 10% of SEER-Medicare decedents experienced ICU care or >1 ER visit in the last month of life. In contrast, 21% of our patients received ICU care and 44% had >1 ER visit in the last month. Three quarters received at least 1 form of intensive EOL care, making such care the norm among young people rather than the exception. Hospice care was used by only 23%, and most deaths occurred in the acute care setting.

AYA cancer patients account for just 2% of patients with invasive cancers in the United States,²⁰ and care is delivered in a variety of settings, including pediatric and adult facilities as well as academic and community cancer centers.^{30,31} In any setting, such patients are atypical and, perhaps as a result, have high rates of unmet needs for information and support during their cancer care,^{32,33} issues that may extend into the EOL setting. Although less is known about EOL care for such patients than it is in older adults at a more advanced life stage, death in this time period is surely no less fraught with complexity. In particular, it is possible that young patients are more willing to accept invasive measures at

the EOL than their older counterparts out of a desire to live as long as possible, and in an effort to support and protect loved ones from the pain of their loss.⁷ Another explanation for the higher intensity care may relate to the greater frequency of hematologic malignancies in the AYA population. In contrast to advanced solid tumor cancers that are not amenable to cure, hematologic cancers are often curable and therefore transitioning from intensive interventions to palliative and supportive care may be more challenging for patients, families, and clinicians. Remarkably, we did not see major differences in the intensity of EOL care based on whether patients had a hematologic cancer or a solid tumor.

State Medicaid plans serve the poor and disabled, often including large numbers of minority patients. For dying AYA cancer patients in New York, these attributes may have added another layer of vulnerability to a group already outside the mainstream. We have previously found similarly low rates of hospice use among stage IV lung cancer patients up to age 64 in New York Medicaid, although the young patients we studied had far higher rates of deaths in acute care (65% among AYAs vs. 36% among lung cancer patients), suggesting that age, race/ethnicity, and poverty may

TABLE 3. Factors Associated With Use of Intensive Measures at the End of Life and With Hospice Utilization Among Adolescent and Young Adult Cancer Patients in NY Medicaid (N = 705)

	Factors Associated With Use of Intensive EOL Care Measures				Factors Associated With Hospice Utilization		
	N	Unadjusted Proportion [n (%)]	AOR (95% CI)	P	Unadjusted Proportion [n (%)]	AOR (95% CI)	P
Race				0.73			0.33
White	447	330 (74)	Reference		108 (24)	Reference	
Black	200	154 (77)	1.07 (0.67, 1.73)		42 (21)	0.74 (0.44, 1.23)	
Asian/other	58	45 (78)	1.36 (0.65, 2.99)		11 (19)	0.59 (0.25, 1.30)	
Ethnicity				0.22			0.13
Hispanic	201	163 (81)	1.37 (0.83, 2.27)		37 (18)	0.67 (0.39, 1.13)	
Non-Hispanic	504	366 (73)	Reference		124 (25)	Reference	
Age at diagnosis (y)				0.02			0.02
15–21	237	164 (69)	Reference		61 (26)	Reference	
22–29	468	365 (78)	1.59 (1.08, 2.35)		100 (21)	0.60 (0.40, 0.91)	
Sex				0.44			0.62
Female	297	222 (75)	Reference		74 (25)	Reference	
Male	408	307 (75)	1.16 (0.79, 1.70)		87 (21)	0.91 (0.61, 1.35)	
Marital status				0.84			0.04
Married	77	58 (75)	Reference		23 (30)	Reference	
Widowed/single/unknown	628	471 (75)	1.07 (0.57, 1.94)		138 (22)	0.52 (0.29, 0.98)	
Median income for zip code of residence				0.48			0.47
Lowest quartile	334	263 (79)	Reference		80 (24)	Reference	
2nd quartile	177	129 (73)	0.78 (0.49, 1.24)		42 (24)	1.02 (0.63, 1.63)	
3rd quartile	121	88 (73)	0.67 (0.39, 1.16)		28 (23)	1.06 (0.59, 1.86)	
Highest quartile	73	49 (67)	0.73 (0.33, 1.64)		11 (15)	0.52 (0.20, 1.28)	
Comorbidity estimate				0.56			0.03
< 13 months of claims	91	56 (62)	1.54 (0.47, 4.81)		20 (22)	0.25 (0.07, 0.84)	
0–1	566	432 (76)	Reference		136 (24)	Reference	
≥ 2	48	41 (85)	1.42 (0.61, 3.71)		5 (10)	0.53 (0.17, 1.36)	
Year of diagnosis				0.20			0.78
2004–2007	442	335 (76)	Reference		101 (23)	Reference	
2008–2011	263	194 (74)	0.78 (0.53, 1.15)		60 (23)	1.06 (0.71, 1.57)	
Diagnosis				0.47			<0.0001
Lymphoma	135	110 (81)	Reference		18 (13)	Reference	
Leukemia	147	113 (77)	1.19 (0.60, 2.32)		14 (10)	0.42 (0.19, 0.95)	
Bone/joint/soft tissue	81	52 (64)	0.63 (0.31, 1.27)		25 (31)	3.16 (1.50, 6.75)	
Testicular or gynecologic	62	49 (79)	1.03 (0.46, 2.39)		18 (29)	2.58 (1.15, 5.80)	
Colorectal	48	35 (73)	0.73 (0.32, 1.71)		23 (48)	7.50 (3.34, 17.31)	
Other	232	170 (73)	0.80 (0.44, 1.40)		63 (27)	2.37 (1.30, 4.49)	
Enrolled in Medicaid at diagnosis	603	466 (77)	1.20 (0.37, 3.68)	0.75	136 (23)	0.26 (0.08, 0.83)	0.03
Continuity of enrollment				<0.0001			0.27
Continuous	462	381 (82)	Reference		106 (23)	Reference	
> 50% enrollment	201	126 (63)	0.36 (0.23, 0.56)		44 (22)	0.66 (0.39, 1.09)	
< 50% enrollment	42	22 (52)	0.22 (0.10, 0.51)		11 (26)	0.66 (0.25, 1.68)	
Geographic region				0.07			0.12
Very large metropolitan	416	331 (80)	Reference		80 (19)	Reference	
Large Urban/suburbs	94	66 (70)	0.89 (0.45, 1.79)		18 (19)	1.34 (0.62, 2.83)	
Urban	95	61 (64)	0.47 (0.27, 0.82)		32 (34)	1.79 (1.00, 3.18)	
Rural/not urban	100	71 (71)	0.74 (0.41, 1.33)		31 (31)	1.84 (1.00, 3.36)	
Basis of eligibility for Medicaid				0.16			0.79
Poverty	509	394 (77)	Reference		120 (24)	Reference	
Disabled/other	196	135 (69)	0.74 (0.48, 1.13)		41 (21)	1.06 (0.67, 1.68)	
Stage				0.04			<0.01
I–III or leukemia	425	308 (72)	Reference		101 (24)	Reference	
IV	280	221 (79)	1.58 (1.03, 2.43)		60 (21)	0.56 (0.37, 0.86)	

AOR indicates adjusted odds ratio; CI, confidence interval; EOL, end of life.

all be relevant factors.²⁷ Black and Hispanic patients are more likely to use aggressive measures at the EOL³⁴ and less likely to use hospice.^{35,36} In addition, families living in poverty may have less ability to leave work and care for a dying young person at home, necessitating higher levels of

inpatient care even near death. Hospice services may be less available in neighborhoods where the poorest patients reside, and oncology clinicians may also not have the resources needed to provide comprehensive attention to complex care needs of the young, poor, often minority patients we studied,

issues that may have all added to the challenges of optimal EOL care delivery.

Our study has some limitations. We found several sociodemographic and clinical characteristics that differed between Medicaid and non-Medicaid-enrolled AYAs, factors that may limit generalizability to the non-Medicaid population. In addition, although our study covered the transition to expanded coverage of young adults by the ACA, few decedents were diagnosed post-ACA, giving us little power to discern differences in care for this group. Given the diversity of cancer diagnoses in young people combined with the small numbers of patients with any 1 cancer type, we evaluated a cohort of patients with a range of diagnoses and prognoses. Even most AYA patients with stage IV cancer lived beyond the study period. Thus, we were unable to reliably identify a group of patients known to be dying from the time of diagnosis. Instead we identified patients prospectively but only evaluated care received by those who died, some of whom may have died due to treatment toxicity rather than advanced cancer. In addition, not all patients were continuously enrolled in Medicaid from diagnosis to death, and we were therefore unable to follow all decedents into the EOL care period. However, by limiting our cohort to patients enrolled in Medicaid in the peridiagnosis period and continuously enrolled in the last 60 days of life, we were able to ensure data capture for the issues salient to our study. Also of note, our models tested multiple associations despite a relatively small sample size and limited power to do so, although similarity of findings across 2 outcomes suggests that results may be clinically meaningful. Finally, while we were able to identify use of intensive measures and hospice, we were not able to account for patient preferences, and similarly could not evaluate processes of communication, such as conversations about prognosis and EOL care, or care processes, such as involvement of palliative care services, that may have influenced patients' decisions about EOL care.

Aggressive care at the EOL is associated with a poorer quality of life near death.¹⁶ Although some patients wish for aggressive care to their last days, most patients who recognize they are dying do not want to receive such care,¹⁴ and instead opt for care focused on managing symptoms and enhancing quality of life. As a result, our findings raise the significant concern that many young people in Medicaid receive poor quality EOL care. Attention to the needs of this vulnerable population is critical to ensure that dying young people with cancer can have the best life possible until its end.

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