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Original Articles

Care in the Final Month of Life among Adolescent and Young Adult Cancer Patients in Kaiser Permanente Southern California

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Abstract

Background: Little is known about the care that adolescent and young adult (AYA) patients with cancer receive at the end of life (EOL).
Objective: To examine care in the last month of life among AYA patients with cancer.
Design: Medical record review of the last 30 days of life.
Setting/Subjects: One hundred eleven AYA patients aged 15–39 years at death with either stage I-III cancer and evidence of cancer recurrence or stage IV cancer at diagnosis. Patients received care in Kaiser Permanente Southern California, an integrated healthcare delivery system, and died from 2007 to 2010.
Measurements: Use of intensive measures, including chemotherapy in the last 14 days of life and emergency room visits, hospitalizations, and intensive care unit admissions in the last 30 days; documented care preferences; symptom prevalence and treatment; advance care planning; hospice use; and location of death.
Results: One hundred seven patients (96%) had documented care preferences in the last month of life. At first documentation, 72% of patients wished for life-prolonging care, 20% wished for care focused on comfort, and 8% were undecided. Forty-seven percent of patients had documented changes in preferences in the last month, with 40% wishing for life-prolonging care when preferences were last noted before death, 56% preferring comfort, and 4% undecided. Seventy-eight percent of patients received at least one form of intensive EOL care, including 75% of those who preferred comfort measures at last documentation.
Conclusions: Many AYA patients enter the last month of life wishing for life-prolonging care. While most ultimately wish for comfort, intensive care is prevalent even among such patients.

Introduction

Although much is known about experiences of older adults who die of cancer, far less is known about experiences of adolescents and young adults (AYAs). AYA patients with cancer represent just 2% of incident cancer cases in the United States.[1] Given the rarity of cancer at a young age, AYA cancer patients differ from their same-aged peers, who are typically healthy, and from the majority of cancer patients, who present at later life stages. Their special position presents challenges in cancer care,[2–5] including near the end of life (EOL).[6–8]

Previous work has called for comprehensive attention to medical and psychosocial needs at the EOL among AYA patients,[5–8] and advance care planning tools have been developed to facilitate thoughtful end-of-life decision-making in this young population.[9,10] We recently evaluated care patterns among 663 AYA cancer patients who died after receiving care within Kaiser Permanente Southern California (KPSC), an integrated health plan and care delivery system.[11] Using electronic health record data, we found that more than two-thirds received intensive measures, such as chemotherapy, inpatient and emergency room care, and intensive care unit care, at the EOL. However, nuanced data on end-of-life care preferences and experiences were not available in electronic health record systems. We are therefore left with unanswered questions, especially about where young cancer patients die, how often patients engage in advance care

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planning and enroll in hospice before death, and why so many young people receive intensive measures at the EOL.

To understand care choices and experiences in more detail, we undertook detailed medical record review of the last 30 days of life for 111 patients aged 15–39 years who received cancer care within KPSC and died between the years 2007 and 2010. The goal of this study was to assess feasibility of assessment of these measures in medical records and to garner initial prevalence data on issues of interest. Medical record review was used to understand patient preferences for care; advance care planning such as do-not-resuscitate orders; symptom prevalence and efforts at symptom management; and hospice use and location of death. In addition, we evaluated the extent to which preferences were associated with intensity of care in the last month of life.

Methods

This retrospective medical record review was conducted as a pilot/feasibility study to evaluate availability of relevant indicators in medical records. We used linked cancer registry and electronic health record data, including clinical notes, within the KPSC health plan to capture data on end-of-life care among AYA decedents with cancer. KPSC is an integrated managed care organization that provides comprehensive health services to ~3.7 million racially/ethnically and socioeconomically diverse members who are broadly representative of residents in Southern California, including San Diego, Los Angeles, and surrounding areas.[12]

Data sources

KPSC maintains clinical databases, including membership, diagnosis, procedures, pharmacy/infusions, utilization, outside claims, and cancer registry, all linkable with a unique member identifier. KPSC medical records include inpatient and outpatient documentation, with the full medical record from all Kaiser hospitals and clinics accessible electronically for the entire study period. KPSC maintains quality standards for documentation and monitors compliance at all institutions. The KPSC Surveillance, Epidemiology, and End Result (SEER)-affiliated cancer registry contains data on all patients who were diagnosed and/or treated for a new cancer since 1988. Quality of the cancer registry data is assured by the SEER standard and is audited by SEER staff on a regular basis.

The IRBs for KPSC and Dana-Farber Cancer Institute approved this study, and requirements for consent were waived.

Cohort formation

We evaluated a randomly selected cohort of 111 KPSC AYA patients who died between 2007 and 2010. This cohort was a subset of a previously established larger cohort of KPSC AYA cancer decedents. We sought to identify patients who died anticipated deaths such that end-of-life care planning would have been appropriate. As described elsewhere,[11] we used KPSC's cancer registry and electronic health records to form a retrospective cohort of decedents who had either stage IV cancer at diagnosis such that prognosis was limited from diagnosis, or stage I-III (nonmetastatic) disease at diagnosis, with evidence of cancer recurrence before death indicated by new metastases or receipt of more than one chemotherapy regimen.[13,14] Included patients (1) died between the years 2007–2010; (2) were aged 15–39 years at death; (3) were diagnosed at least 30 days before death such that end-of-life care indicators were evaluable; and (4) were enrolled in the health plan during the month of death such that end-of-life care indicators could be found in available records. Our sample size goal for pilot/feasibility purposes was 100 patients, a number expected to offer robust initial data for further study. Charts for 111 cohort patients were reviewed, slightly more than initially planned, including 54 patients with stage IV disease and 57 patients with stage I-III disease and recurrence. Review was limited to the last 30 days of life.

Measures

Medical record review was used to evaluate patient and disease characteristics; patient/family care preferences; symptoms; advance care planning; and location of death. Most measures, such as symptoms, use of hospice, and location of death, reflect care experiences. However, select measures, such as treatment preferences and care planning, reflect patients' care wishes/choices. Although most measures were readily abstracted as quantitative data, abstraction of treatment preferences had a qualitative component detailed below.

Patient and disease characteristics were collected from electronic health records and registry data, including dates of birth, diagnosis, and death; gender; race/ethnicity; cancer type; stage at diagnosis; and census block income and educational level. Previously developed measures of end-of-life care intensity,[15–17] adapted for use in KPSC's electronic health records, included chemotherapy within 14 days of death; intensive care unit care within 30 days of death; more than one emergency room visit within 30 days of death; and hospitalization within 30 days of death.

Patient/family preferences for care were assessed when medical records included documentation of discussions with patients or family members about patients' wishes for the aggressiveness of care. Preferences were categorized as (1) a preference for life-prolonging care, as indicated by a preference for care directed at life prolongation or cure and/or using all possible measures; (2) a preference for comfort-focused care, as indicated by statements that the patient wished for measures directed at comfort, symptom management, or palliation; or (3) undecided preference, when preferences were elicited, but patients/family members did not reach a decision about the direction of care. While the study was not qualitative *per se*, abstraction of preferences required abstractors to recognize relevant statements and draw conclusions about patient preferences on the basis of those statements. Therefore, to further evaluate the ability of abstractors to classify preferences, the relevant statement was abstracted from the medical record for review by the full study team. Because some patients had more than one discussion about preferences during the last month of life, and because some patients' preferences changed in the last month, each statement of preferences on a different date was recorded as a separate event.

Symptoms in the last month of life, including pain, dyspnea, fatigue, nausea, vomiting, diarrhea, constipation, and depression, were documented as present if medical records noted such symptoms any time in the last 30 days of life; as absent if records noted the absence of such symptoms; or as unknown if no documentation about whether symptoms were present or absent was found. Each symptom was evaluated separately. If the symptom was present, notation was made of documented efforts to treat the symptom, including any pharmacy record of medications appropriate for treating the symptom.

Medical records were also used to evaluate the presence and timing of do-not-resuscitate orders, designation of a healthcare proxy, and use of hospice. Because review was limited to the last 30 days of life, the timing of each was designated as the number of days before death if the event occurred in the last 30 days of life or as having occurred before the last 30 days of life.

Location of death was categorized as the intensive care unit, the hospital, but not the intensive care unit, home, or other for all patients with documentation of location of death. For patients without such documentation and without inpatient care on the last day of life, location was categorized as unknown.

Statistical analysis

Data on the prevalence of end-of-life measures, including intensive end-of-life care measures, preferences, symptoms, advance care planning, hospice use, and location of death, were generated as the percentage of decedents experiencing each measure. For the measures of end-of-life care intensity, a summary measure indicating receipt of any of the four measures of intensive end-of-life care was also generated. Chi-squared tests or Fisher's exact tests were used to compare differences in the proportion of patients receiving any intensive measure according to care preferences.

Results

Nearly half of patients were non-Hispanic white (49%), with the remainder identified as black (10%), Asian (14%), Hispanic (27%), or other race/ethnicity (1%, Table 1). More than three-quarters of patients received at least one form of intensive end-of-life care (78%, Table 2), including chemotherapy within 14 days of death (11%), care in the intensive care unit (29%), more than one emergency room visit (30%), or hospitalization within the last month of life (73%).

Discussions about care preferences were documented for 96% of patients ($N = 107$). At the time, preferences were first documented during the 30-day review window, 72% of patients or family surrogates preferred life-prolonging care (Table 3). Example statements included ''The patient's spouse and family want all possible treatments at this time. They wish for the patient to live as long as possible and spend as much time as possible with her family'' and ''At this time they are still wishing to pursue aggressive care. Code status: the patient remains full code.'' Twenty percent of patients/family members preferred care focused on comfort when preferences were first documented. Example statements included ''After discussion of the risks and benefits, mother and father decided that they do not desire resuscitation or intubation. They want [patient] to be comfortable and not suffer'' and ''Patient does not want to continue with further chemo… 'I just want to be as comfortable and free as possible at home.''' A minority of patients/families took part in discussions about preferences, but remained undecided about their wishes for care (8%).

Table 1. Characteristics of the Study Cohort ($N = 111$)

Characteristic	N *(%)*
Age at death (years)	
15–24	23 (20.7)
25–34	36 (32.4)
35–39	52 (46.8)
Male gender	53 (47.7)
Race/ethnicity	
White	54 (48.6)
Black	11 (9.9)
Asian	15 (13.5)
Hispanic	30 (27.0)
Other	1 (0.9)
Cancer type	
Leukemia	7 (6.3)
Lymphoma	15 (13.5)
Bone/soft tissue	2 (1.8)
Gastrointestinal	21 (18.9)
Genitourinary	16 (14.4)
Breast	11 (9.9)
Lung	7 (6.3)
Brain	13 (11.7)
Other	19 (17.1)
Stage at diagnosis	
I–III	57 (51.4)
IV	54 (48.6)
Income level, median for census tract	
<$40,000/year	28 (25.2)
$40–65,000/year	43 (38.7)
>$65,000/year	40 (36.0)
Education (% with a college degree within census tract)	
<25	71 (64.0)
25–49	31 (27.9)
50–74	9 (8.1)
≥75	0 (0.0)

Nearly half of patients/families (44%, $N = 47$) subsequently had different preferences documented before death, with 40% ultimately wishing for life-prolonging care, 56% preferring comfort measures, and 4% undecided. Patients and families who wished for life-prolonging care at the time of last documentation of preferences were no more likely to receive intensive measures at the EOL (88%, Table 4, $p = 0.18$) than those who preferred care focused on comfort (75%) or were undecided (75%); most patients received intensive measures regardless of their last stated preferences.

Table 2. Prevalence of Intensive End-of-Life Care among the 111 Patients in the Study

	N *(%)*
Chemotherapy within 14 days of death	12 (10.8)
Intensive care unit care within 30 days of death	32 (28.8)
>1 Emergency room visit within 30 days of death	33 (29.7)
Hospitalization within 30 days of death	81 (72.9)
Any of the above	87 (78.4)

Table 3. Patient Preferences for Care among 107 Patients (96.4% of 111) with Documented Preferences or Discussion of Preferences

Care preference within the last 30 days of life	*Earliest documented preference within last 30 days of life,* N *(%)*	*Last documented preference before death,* N *(%)*
Prefers care focused on cure or prolongation of life	77 (72.0)	43 (40.2)
Prefers care focused on palliation of symptoms	21 (19.6)	60 (56.1)
Undecided	9 (8.4)	4 (3.7)

Symptoms were prevalent in the last month of life, including pain (94%), dyspnea (59%), fatigue (79%), nausea (68%), vomiting (59%), diarrhea (23%), constipation (59%), and depression (41%, Table 5). More than 90% of patients experiencing each symptom received treatment for the symptom, except for fatigue (47% of patients experiencing fatigue had documented efforts to treat), depression (43%), and diarrhea (68%).

Two-thirds of patients had do-not-resuscitate orders in place before death (67%). Among patients with do-not-resuscitate orders, 11% ($N=8$) were in place before the start of the 30-day medical record review period; the remainder were placed in the last month of life at a median of 4 days before death (interquartile range 1–12 days before death among patients whose do-not-resuscitate orders were placed in the last month); 32% of patients had a healthcare proxy documented in the medical record. Fifty-five percent of patients enrolled in hospice before death, with 41% ($N=25$) of those in hospice enrolled before the last month of life and 59% ($N=28$) enrolled during the last month at a median of 11 days before death (interquartile range 4–20 days among those who enrolled in the last month), 14% of patients died in the intensive care unit, and 27% died in other inpatient hospital settings. Remaining patients had documented home deaths (18%), deaths in other documented locations (2%), or no documented location (40%) and no inpatient care on the date of death, suggesting outpatient/home death.

Discussion

We recently documented high rates of intensive measures at the EOL among AYA cancer patients.[11] However, the reasons for this finding were incompletely understood, and we lacked more nuanced data on end-of-life care experiences. We therefore undertook a more detailed look at end-of-life care preferences, planning, and experiences among AYA cancer patients using in-depth medical record review. Although we found that nearly three-quarters of patients entered the last month of life wishing to receive all possible measures to prolong life, over half ultimately wanted comfort measures before death. Along similar lines, most patients ultimately had do-not-resuscitate orders in place and enrolled in hospice. Despite this move toward comfort measures, however, most patients received intensive measures in the last month regardless of their ultimate preferences for care.

Although intensive measures at the EOL are often considered undesirable, young people may wish to receive every possible intervention to live as long as possible, especially in service to a life not fully lived or to children, parents, and partners who wish for more time. This view in particular may reflect the perspective of the 40% of patients who expressed a wish for life-prolonging care until the end of their lives. Others ultimately chose care focused on comfort, but typically also requested and received life-prolonging measures within the last month of life. It remains unknown whether a move toward comfort measures could have happened earlier in the trajectory of illness or whether this care pattern simply reflected challenging end-of-life decision-making among young people. Previous work in older adults suggests that early integration of palliative care[18] and early conversations about end-of-life care[19] can both lead toward greater use of comfort measures. Advance care planning tools have also been developed for the AYA population, with the potential to enhance decision-making[9,10]; these interventions may have been helpful for the young patients we studied.

We also do not know how patients and family members would have assessed the quality of end-of-life care received; it is possible that these patients, in pursuing life-prolonging measures until just before the end, received exactly the care they wanted. Of note, we found high rates of documented symptoms, suggesting that the last month of life involved at least some degree of suffering for most patients. However, in nearly all cases, symptoms were accompanied by high rates of attempts to treat them. This represents one way in which palliation was integrated across care preferences.

Limitations

Although we assessed patient preferences, our review was limited to the last month of life; earlier discussions about preferences could not be captured. However, nearly all patients had such discussions in the last month, with preferences

Table 4. Use of Intensive End-of-Life Measures According to Last Documented Preferences

Last documented preferences for care	*Total* N	N *(%) who received any intensive measures*	N *(%) who received no intensive measures*
Prefers care focused on cure or prolongation of life	43	38 (88.4)	5 (11.6)
Prefers care focused on palliation of symptoms	60	45 (75.0)	15 (25.0)
Undecided	4	3 (75.0)	1 (25.0)

Chi-square test for differences in proportions, $p=0.18$.

Table 5. Symptom Prevalence and Management

	N *(%) with symptom documented as present*	N *(%) with symptom documented as absent*	N *(%) with symptom unknown (not documented as present or absent)*	*Of those with symptom,* N *(%) who received treatment for symptom*
Pain	104 (93.7)	6 (5.4)	1 (0.9)	103 (99.0)
Dyspnea	65 (58.6)	41 (36.9)	5 (4.5)	64 (98.5)
Fatigue	88 (79.3)	6 (5.4)	17 (15.3)	41 (46.6)
Nausea	76 (68.4)	22 (19.8)	13 (11.7)	76 (100.0)
Vomiting	66 (59.5)	32 (28.8)	13 (11.7)	66 (100.0)
Diarrhea	25 (22.5)	59 (53.2)	27 (24.3)	17 (68.0)
Constipation	65 (58.6)	39 (35.1)	7 (6.3)	59 (90.8)
Depression	46 (41.4)	36 (32.4)	29 (26.1)	20 (43.5)

clearly documented. Documentation of preferences is considered a marker of high-quality end-of-life care[20,21] and offered evidence of feasibility of ascertainment of preferences from medical records. We abstracted full statements because we anticipated some challenges in categorizing preferences. In our initial review, we tried to identify a desire to pursue a cure separately from preferences for life-prolonging care, but found that the distinction could not be made reliably. We therefore combined these into a single measure, despite the fact that individual patients may see these choices quite differently. We also anticipated identifying some patients whose goals incorporated elements of life prolongation and comfort measures, such as patients who wanted to live as long as possible, but with the best quality of life possible. Instead, we found that documented preferences were generally readily categorized. It is possible that medical records failed to capture the nuance of preferences for some patients with mixed goals. Finally, although documented preferences showed that just over half of patients and families wished for comfort measures at the EOL, even more patients had do-not-resuscitate orders in place before death, suggesting that more patients transitioned to comfort measures before death without explicitly documented discussions. Similarly, although we know that many patients received hospice care, we do not know how often hospice was offered to remaining patients. A lack of hospice use could reflect a physician decision not to offer hospice or patient refusal. Thus, documentation in medical records may have failed to capture some important events, conversations, and decisions.

Finally, because we focused on decedents, our understanding of their experiences is limited to what is noted in medical records. Ideally, patients themselves would be able to report on their perspectives and experiences prospectively. Future work should therefore include efforts to incorporate the voices of patients and their family members. However, despite the inherent limitations of chart review, our study provides new insight into the care received by young people dying of cancer, a group whose perspectives are still not well understood.

Conclusions

We selected a patient population with poor prognoses by virtue of stage IV disease at diagnosis or evidence of recurrence, a strategy that was confirmed by medical record evidence of anticipated death in nearly all of our patient population. Thus, these patients should have had some opportunity to plan for end-of-life care. In addition, nearly all patients or families were engaged in discussions about preferences for care, suggesting that medical providers were working to make care plans that accounted for the patients' poor prognoses. Even so, many patients wanted, and received, aggressive measures near death. Although there is still much to be learned about the wishes of dying young people and their perspectives on optimal end-of-life care, clinicians should continue efforts to understand individual perspectives, offering early conversations while also recognizing the potential for AYA patients' preferences to evolve in the days near death. At the very least, such conversations will help clinicians to understand and implement care preferences, whether for aggressive or comfort-directed care, so that end-of-life care reflects the values of young people as they approach death.

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Author Disclosure Statement

No competing financial interests exist.

References

1. Bleyer A, Viny A, Barr R: Introduction in *Cancer Epidemiology in Older Adolescents and Young Adults 15 to 29 Years of Age, Including SEER Incidence and Survival: 1975–2000.* Bleyer A, O'Leary M, Barr R, Ries LAG (eds). National Cancer Institute, NIH Bethesda, MD, 2006.
2. Bleyer A: The adolescent and young adult gap in cancer care and outcome. Curr Probl Pediatr Adolesc Health Care 2005;35:182–217.
3. Bleyer A, Budd T, Montello M: Adolescents and young adults with cancer: The scope of the problem and criticality of clinical trials. Cancer 2006;107(7 Suppl):1645–1655.
4. Zebrack BJ, et al.: Psychosocial service use and unmet need among recently diagnosed adolescent and young adult cancer patients. Cancer 2013;119:201–214.
5. Zebrack B, Mathews-Bradshaw B, Siegel S: Quality cancer care for adolescents and young adults: A position statement. J Clin Oncol 2010;28:4862–4867.
6. Wein S, Pery S, Zer A: Role of palliative care in adolescent and young adult oncology. J Clin Oncol 2010;28:4819–4824.

7. Coccia PF, et al.: Adolescent and young adult oncology. Clinical practice guidelines in oncology. J Natl Compr Canc Netw 2012;10:1112–1150.
8. Walter JK, Rosenberg AR, Feudtner C: Tackling taboo topics: How to have effective advanced care planning discussions with adolescents and young adults with cancer. JAMA Pediatr 2013;167:489–490.
9. Wiener L, et al.: Allowing adolescents and young adults to plan their end-of-life care. Pediatrics 2012;130:897–905.
10. Lyon ME, et al.: Family-centered advance care planning for teens with cancer. JAMA Pediatr 2013;167:460–467.
11. Mack JW, Chen LH, Cannavale K, Sattayapiwat O, Cooper RM, Chao CR: End-of-life care intensity among adolescent and young adult patients with cancer in Kaiser Permanente Southern California. JAMA Oncol 2015;1:592–600.
12. Koebnick C, et al.: Do the sociodemographic characteristics of members of a large, integrated health care system represent the population of interest? Perm J 2012;16:37–41.
13. Cooper GS, et al.: The utility of Medicare claims data for measuring cancer stage. Med Care 1999;37:706–711.
14. Earle CC, et al.: Identifying cancer relapse using SEER-Medicare data. Med Care 2002;40(8 Suppl):IV-75–81.
15. Earle CC, et al.: Trends in the aggressiveness of cancer care near the end of life. J Clin Oncol 2004;22:315–321.
16. Earle CC, et al.: Evaluating claims-based indicators of the intensity of end-of-life cancer care. Int J Qual Health Care 2005;17:505–509.
17. Goodman D, et al.: *Trends in Cancer Care Near the End of Life: A Dartmouth Atlas of Health Care Brief*. The Dartmouth Institute for Health Policy and Clinical Practice, Lebanon, NH. 2013.
18. Temel JS, et al.: Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 2010; 363:733–742.
19. Mack JW, et al.: Associations between end-of-life discussion characteristics and care received near death: A prospective cohort study. J Clin Oncol 2012;30:4387–4395.
20. Dy SM, et al.: Measuring what matters: Top-ranked quality indicators for hospice and palliative care from the american academy of hospice and palliative medicine and hospice and palliative nurses association. J Pain Symptom Manage 2015;49:773–781.
21. Palliative and end-of-life care performance measures. www.qualityforum.org (Last accessed June 1, 2015).

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