UC Davis UC Davis Previously Published Works

Title

Inpatient utilization and disparities: The last year of life of adolescent and young adult oncology patients in California.

Permalink https://escholarship.org/uc/item/0dc4c7w9

Journal Cancer, 124(8)

Authors

Johnston, Emily Saynina, Olga Sanders, Lee <u>et al.</u>

Publication Date

2018-04-15

DOI

10.1002/cncr.31233

Peer reviewed



HHS Public Access

Author manuscript *Cancer.* Author manuscript; available in PMC 2019 April 15.

Published in final edited form as: *Cancer.* 2018 April 15; 124(8): 1819–1827. doi:10.1002/cncr.31233.

Inpatient Utilization and Disparities: The Last Year of Life of Adolescent and Young Adult Oncology Patients in California

Emily E Johnston, MD¹, Elysia Alvarez, MD¹, Olga Saynina, MBA², Lee Sanders, MD^{2,3}, Smita Bhatia, MD⁴, and Lisa J Chamberlain, MD^{2,3}

¹Division of Pediatric Hematology/Oncology, Stanford University School of Medicine

²Center for Health Policy and the Center for Primary Care and Outcomes Research, Stanford University

³Division of General Pediatrics, Stanford University School of Medicine

⁴Institute for Cancer Outcomes and Survivorship, School of Medicine, University of Alabama at Birmingham

Abstract

BACKGROUND—Studies of AYA oncology end-of-life care utilization are critical as cancer is the leading cause of non-accidental AYA death and end-of-life care contributes significantly to healthcare expenditures. We sought to determine the quantity of and disparities in inpatient utilization in the last year of life of AYAs with cancer.

METHODS—Using the California Office of Statewide Health Planning and Development administrative discharge database linked to death certificates, we performed a population-based analysis of cancer patients aged 15–39 who died 2000–2011. We determined the number of hospital days and inpatient costs for each patient in their last year of life and clinical and sociodemographic factors associated with high inpatient utilization. We also evaluated admission patterns as death approached.

RESULTS—The 12,883 patients were admitted 40 days on average in the last year of life, costing \$149,307 per patient in inpatient costs. As death approached, admission rates and the percent of all admissions occurring at non-specialty centers increased. 5% of patients used 20% of bed-days in the last year (high-utilizers). Factors associated with high utilization included younger age (15–30 years), Hispanic ethnicity, non-HMO insurance, and hematologic malignancies.

CONCLUSIONS—AYA oncology decedents spent 40 days admitted in their last year of life. Subgroups with high utilization had distinct sociodemographic and clinical characteristics and

Author Contributions:

Corresponding Author: Emily Johnston, MD, Pediatric Hematology/Oncology, 1000 Welch Road, Suite 300, Palo Alto, CA 94304, (650) 723-5535, (650) 723-5231(fax), emilyj@stanford.edu.

Disclosures: The authors have no disclosures or conflicts of interest to report.

Conceiving and designing the study: Johnston, Alvarez, Sanders, Bhatia, Chamberlain Data acquisition and analysis: Saynina

Data interpretation: Johnston, Alvarez, Sanders, Bhatia, Chamberlain

Manuscript Drafting: Johnston

Critically revised the manuscript: Alvarez, Saynina, Sanders, Bhatia, Chamberlain

non-specialty center admissions increased as death approached. This demonstrates the need for palliative care at non-specialty centers. Future studies need to determine if these patterns are goal-concurrent, include high utilizers, and monitor the effect of healthcare reform.

Keywords

End-of-life; oncology; adolescent; young adult; intensity; utilization

INTRODUCTION

Cancer is the leading cause of non-accidental death among adolescents and young adults (AYAs – aged 15–39) in the US,^{1,2} making end-of-life care a critical aspect of AYA oncology. End-of-life care also has important implications for healthcare costs. Over 10% of the US healthcare budget³ and over 25% of Medicare claims are devoted to the last year of life.⁴ However, there is a paucity of information regarding AYA oncology end-of-life care in general and almost none on AYA oncology end-of-life healthcare utilization.² Utilization studies are key given our healthcare expenditures and potential legislation that may limit access.

It is imperative that we determine AYA oncology patients' hospital utilization in the last year of life, in order to determine the burden of end-of-life care on the healthcare system, patients, and families. This information can then be used to determine if the utilization patterns are due to patient preference or are influenced by other factors such as provider preference or resource availability. While there has been an impressive growth in palliative care programs in the US in the last 15 years, they are not evenly distributed; palliative care programs are more commonly housed in larger hospitals and in certain regions of the US.⁵ Determining the prevalence and patterns of healthcare use in the last year of life for AYAs with cancer is important in order to begin to examine the appropriate distribution of palliative care resources. Therefore, we sought to determine AYA cancer decedents' inpatient utilization in the last year of life at a population level.

PATIENTS AND METHODS

Study Design and Oversight

We conducted a retrospective (2000–2011) population-based analysis using the California Office of Statewide Health Planning and Development (OSHPD) Private Patient Discharge Data database linked to the Vital Statistics Death Certificate Data File. The database contains data on all inpatient discharges from all California hospitals except federal facilities and prison hospitals. OSHPD includes the following information on each discharge: age, race/ethnicity, sex, zip code of residence, payer status, length of stay, charge, and up to 24 ICD-9 codes. Stanford University IRB and the State of California Committee for Protection of Human Subjects approved the study. Guidelines for reporting of studies using administrative data were followed.⁶

Study Population

The study population included patients aged 15–39 at the time of death, who died 2000– 2011, and had an oncologic ICD-9 code during a hospitalization within six months of death or cancer as a death certificate cause of death but did not die of peripartum events or trauma to help ensure that patients were dying of cancer, not with cancer. (Figure 1). We could only examine patients with record linkage numbers. In order to have complete data and accurate on patients, we also excluded patients that were non-California residents (n=204) and patients that had non-sensical information in their records such as admissions after date of death (n=51). Before removing the last group of eligible patients due to non-California residency, non-sensical information, or potential death due to peripartum event or trauma, there were 13,352 patients identified. 11,335 (85%) of the 13,352 were identified both by a cancer ICD-9 during an admission and cancer ICD-10 on their death certificate, 785 (6%) on death certificates only and 1212 (9%) through cancer ICD-9 only. Of the 785 without an admission with a cancer ICD-9, only 123 were admitted but did not have a cancer ICD-9 during their admission – the rest were not admitted in the last 6 months of life. An initial list of oncologic ICD-9 codes were developed by combining the oncologic diagnosis in the Clinical Classification Software⁷ and oncologic ICD 9 codes previously used in OSHPD.⁸ Death certificate cause of death categories for malignant neoplasms (C00-C97) were included. Potential non-malignant conditions were excluded such as carcinomas-in-situ and abnormal Papanincolaou smears as were patients who died of accidents or peripartum events. The resulting ICD-9 codes were grouped according to Surveillance, Epidemiology, and End Results Program (SEER) AYA Site Categories.⁹ Four oncologists independently reviewed the list for completeness and accuracy.

Study Variables

Independent Variables—The socio-demographic variables included payer status, age, gender, race and ethnicity, median household income (from zip code median household income categorized by the 2004 federal poverty level), and distance from residence to the 1) nearest specialty center, 2) nearest hospital, 3) last hospital used. Specialty centers were defined as Children's Oncology Group (COG) centers for those less than 18, National Cancer Institute or COG for those 18 or older. Patients were classified according to AYA SEER categories through ICD-9 codes as described above.

Elixhauser's enhanced comorbidity score was chosen as a comorbidity index because it was developed with the OSHPD database and included oncology patients.^{10,11} Each patient scored one point for each non-oncologic comorbidity category present during their final admission.¹² Payer status and comorbidities were determined from the last hospital admission before death. Location of death was determined from death certificate or disposition of death on a terminal admission. The remainder of the variables were determined from the death certificate unless missing on the death certificate and were then abstracted from the last hospital admission.

Dependent Variables—The number of unique admissions and number of days admitted in the last year of life were calculated, excluding admissions with ICD-9s for accidents (except medical errors) and peripartum care. AYA decedents with high utilization rates,

"high utilizers", as determined by total bed days were calculated using a Pareto analysis – which plots how resources are distributed throughout a population. We plotted what percent of patients used what percent of the total end-of-life bed days for the cohort. The corresponding Gini coefficient was calculated. Gini coefficients quantify the difference between a given distribution and the perfectly equal distribution (where each one percent of the population takes up one percent of bed days) and are frequently used to describe a country's income distribution. A Gini Coefficient of zero corresponds to perfect equality of distribution and a Gini coefficient of one perfect inequality. The US income distribution has a Gini Coefficient of 0.48.¹³

Cost Calculation

OSHPD includes charge but not cost information and each hospital's financial information. Hospital specific ratios of cost to charge [RCC: (Total Operating Expenses-Other Operating Revenue)/Total Gross Patient Revenue)] were calculated. The RCC multiplied by charge was then used to determine costs.^{14–15} One HMO system did not report charges to OSHPD so patients admitted to their system (1776 patients, 13.7% of the study population) were excluded from the cost analysis. Costs were adjusted to 2016 US dollars.

Statistical Analysis

Descriptive statistics were calculated for each independent and dependent variable above. The percent of the population admitted each day was calculated for the population as a whole and for each subset of the population (diagnosis, age, etc.). The percent of admissions at specialty versus non-specialty centers was calculated each month. Admissions were attributed to the month the admission started.

A logistic regression model was constructed to determine associations with being a high utilizer (top 5% of bed-day users). All clinical and sociodemographic variables were included in the univariate analysis. Due to concerns for colinearity, the distribution in the population, and the univariate results, distance to last hospital was retained for the multivariable model, but distance to specialty center, distance to closest hospital, and urban/rural status were not. The rest of the independent variables were chosen *a priori* and retained for the regression analysis. For sensitivity analysis, we also conducted a regression analysis without location of death in case hospital death was so highly associated with increased utilization that it would skew the remainder of the results. Given how diagnosis and age are inter-related, we examined the interaction between diagnosis and age. Test for trend analysis was conducted for age and year of death. We present adjusted odds ratios (OR) and 95% confidence intervals (CI). SAS version 9.1 (SAS Inc., Cary, NC) was used.

RESULTS

Study Population Characteristics

The final study population included 12,883 patients and had the expected clinical and sociodemographic breakdowns for a cohort of terminal AYA oncology patients in California (Table 1). In particular, 65% of the study population was 31 or older, 61% of the population had solid tumors, 39% hematologic malignancies, 95% were admitted in the last six months

of life, and most patients (70%) were admitted to a community center at least once in their last 6 months of life. The largest racial/ethnic group was non-Hispanic white (46%) followed by Hispanics (30%). Almost half of the population (48%) was publically insured.

Last Year Overall Utilization/Cost

AYAs dying of cancer spent a mean of 40 days (Standard Deviation (SD): 42) in the hospital in their last year of life, with a mean cost of \$149,307 (SD: \$201,451). Most of their admissions and inpatient expenses occurred in the last 6 months of life: in the last 6 months they spent a mean of 32 days in the hospital (SD: 34), with a mean cost of \$124,444 (SD: \$175,816).

In the last year of life, hospital admissions were not evenly distributed throughout the population. In particular, 5% of the patients used 20% of the bed-days and 20% of the patients, 53% of the bed days (Figure 2). The associated Gini Coefficient was 0.49.

Factors Associated with High Bed Utilization in the Last Year of Life

Being in the top 5% of utilizers in the last year of life was associated with younger age [15-21 years: OR 2.85 (95% CI 2.27-3.58), 22-30 years: OR 1.81 (1.48-2.22)], Reference: 31-39 years], Hispanic ethnicity [OR 1.51 (1.23–1.86), Reference: Non-Hispanic white], and non-HMO insurance [private: OR 1.48 (1.06–2.04), public/self pay: OR 1.84 (1.34–2.50)], Reference: HMO insurance]. Additionally, patients with hematologic malignancies were more likely than those with solid tumors to be high utilizers [OR 3.11 (2.56–3.78)]. Admission only at a specialty center was also associated with being a high utilizer [OR 1.64 (1.36–1.97): Reference: not-always specialty]. Additionally, there were more high utilizers at the end of the study period than at the beginning [2004–2007: OR 1.38 (1.12–1.71), 2008-2011: OR 1.38 (1.11-1.72), Reference: 2000-2003] (Table 2). Other factors associated with increased utilization were distance from final hospital to home and dying in the hospital. Analysis without location of death changed magnitude of associations (up to 20%) but did not change direction of associations or significance. Additionally, analysis of the interaction between age and diagnosis showed 1) At all ages patients with hematologic malignancies were more likely to be high utilizers 2) For both diagnosis groups, patients 15– 21 were more likely to be high utilizers than patients 22–29, who were more likely to be high utilizers than patients 30–39 (data not shown). However, test for trend analysis showed that the age and outcome relationship were not linear (data not shown).

Patterns in the Last Year of Life

As death approached, the percent of the population admitted at a given time increased (Figure 3). Each subgroup analyzed (age, diagnosis, payer status, hospital type) was distinct in detail towards the end-of-life, but the overall pattern for utilization for each subgroup did not change. As death approached, an increasing percentage of the admissions occurred at non-specialty centers with 70% of admissions occurring at non-specialty centers in the last month before death (Figure 3). There was a slight trend towards admissions occurring at hospitals closer to home (Figure 3). Admissions 12 months from death were a mean of 24.4 miles from the patients' home and admissions within the last month of death were 20.3 miles from home, but this was not a statistically significant difference.

DISCUSSION

AYAs dying of cancer in California spent an average of 40 days admitted at a cost of \$149,000 per patient in inpatient costs in their last year of life. This may be unwanted by families and may represent an unneeded burden on the healthcare system. This is the first study to determine AYA oncology patient's hospital utilization in their last year of life, and these results appear consistent with the limited existing literature: In British Columbia, oncology patients spent an average of 20-25 days in the hospital in their last year¹⁶ and, in Australia, just over 40.¹⁷ The cost data also appears consistent with the existing literature: the average inpatient costs for a cohort of older cancer patients (average age 62) in the last 6 months of life were \$40,702 in 2009 dollars - just over \$45,000 in 2016 dollars (compared to \$124,000 in our study).¹⁸ As younger patients and non-HMO patients had higher utilization in the last year and our data is a younger cohort and the cost data lacks some HMO cost information, it is not surprising that our costs are higher than in the older cohort. What is unknown, is whether this utilization is consistent with goals of care for AYA oncology patients and how many bed days are preventable through better home services or earlier prognosis discussion. It has been shown that end-of-life conversations are associated with lower costs in older cancer patients (and higher quality of life) in the last week of life.¹⁹ However, the impact of end-of-life conversations on health care earlier in the year is unknown. The number of days at home as death approaches has been suggested as a quality marker for end-of-life oncology care.²⁰ Therefore, it will be important to determine if it is an appropriate AYA oncology marker and, if appropriate, what the benchmark should be. This AYA end-of-life cost and utilization analysis establishes a baseline that will allow for monitoring as changes to the Affordable Care Act (ACA) potentially limit home resources, the advent of immunotherapy changes prognostic conversations, and there is continued growth of palliative care programs. This is particularly critical to monitor as there was increased utilization later in the study period.

Not all patients and families contributed to this utilization and cost equally – as evidenced by the Gini coefficient of 0.49. There were both sociodemographic and clinical disparities in AYA oncology utilization in the last year of life that appear to drive this inequitable distribution. Sociodemographic factors associated with increased utilization included: vounger age, Hispanic ethnicity, non-HMO insurance, and living farther from the hospital. Clinical factors associated with increased utilization included admission at specialty centers and hematologic malignancies. This is consistent with international and Medicare studies that show end-of-life utilization varies with diagnosis, ^{21–27} age, ^{17,26,28} gender, ^{22,24} race/ ethnicity.^{22,24} socioeconomic status.²⁶ and comorbidities.²⁹ Again, it is unknown if these disparities are due to patient preference or other factors such as provider preference, local hospice availability, or delayed end-of-life conversations, among others. Therefore, it is critical to include known high utilizer populations in studies of end-of-life preferences in order to discern the underlying cause, and for providers to be aware of this disparity when providing end-of-life care. This suggests that further studies of HMO systems are warranted to determine if they are decreasing utilization (and costs) in a goal concurrent manner. If so, the HMO model may provide ideas for potential end-of-life interventions that can decrease costs and increase end-of-life care quality. Finally, applying the Gini coefficient to determine

As death approaches, patients were admitted with increased frequency and a higher percentage of those admissions occurred at non-specialty centers. This increased utilization as death approaches is not surprising and has been previously showed in Australian²² and Canadian²⁶ cancer patients. However, the increased non-specialty center utilization at endlife life is a new finding that needs to be further explored to determine how such utilization affects goal concurrent care for AYAS dying of cancer. Some of the increased non-specialty center utilization may be driven by patients choosing to be admitted closer to home as they near the end-of-life as there was a slight decrease in distance from admission hospital to home as death approached. However, we previously showed that AYAs admitted to nonspecialty centers were more likely to receive medically intense end-of-life care (cardiopulmonary resuscitation, intubation, etc.) than those admitted to specialty centers at end-of-life.³⁰ Therefore, it appears that there is different end-of-life care at the two locations: community centers are less likely to see the high utilizers, but they increasingly see patients as death approaches and the patients they see are more likely to have medically intense interventions. We need to determine if this is consistent with patient goals - do patients at specialty centers want to spend more time in the hospital and do patients at community centers want to have medically intense interventions? Regardless, there are important implications for clinicians and community hospital programs as 70% of AYA oncology admissions in the last month of life occur at non-specialty centers it is imperative that they have the resources and information to care for AYAs dying of cancer. We need to be sure that 1) non-specialty center physicians are well-versed in AYA end-of-life best practices, 2) palliative care programs are available at both specialty and non-specialty centers, 3) non-specialty centers have strong relationships with local hospice agencies, and 4) there is good communication between specialty center clinicians initially caring for these patients and the non-specialty center clinicians that are providing end-of-life care. This nonspecialty center utilization at end-of-life may increase further if there are cuts to Medicaid, making considerations of palliative care resource distribution and training critical.

This full population study has limitations that should be considered. It is limited to California patients, but as over 10% of the US population resides in California and as California is a diverse state, it has important implications.³¹ Only patients in the linked hospital admission and death certificate database are included in the study. Therefore, we miss patients that were not admitted at any point in their lives, patients only admitted in other states, at prison or VA hospitals, or patients without record linkage numbers. There are 2777 patients in the death certificate database alone that meet our inclusion criteria. If they were never admitted, it would bias our results towards more inpatient utilization and costs in the last year of life and bias our results towards a less skewed distribution of admissions in the last year of life. As 95% of the study population was admitted in the last six months of life, the number of AYA oncology patients never admitted is most likely small. Additionally, 44% of the 2777 unlinked patients died in the hospital – therefore we know that almost half of those patients were admitted at some point in their lives but were not included due to admission at a non-qualifying hospital (VA, prison, or out of state) or lacked a record

linkage number. This a deceased patient study, which has limitations when compared to prospective studies of actively dying patients.³² This study includes all patients that died, rather than just those who died due to their disease and not treatment related mortality. In a prospective death cohort study we could study patients that had a sentinel event such as relapse that meant they were expected to die rather than just all patients that died and examine their healthcare utilization once they received a terminal diagnosis. Deceased patient studies frequently restrict themselves to patients with known terminal disease - stage IV diagnosis or relapse to ensure they are only looking at patients who should potentially have a palliative approach to care, rather than patients who die of treatment related mortality. However, staging and relapse information is not available in the OSHPD database. Instead, this study gives us broad overview of end-of-life utilization for a full population - data which is not currently available for prospective studies of death. Additionally, with the emergence of immunotherapy and other new treatment paradigms, accurate prognostication becomes increasingly challenging for clinicians and researchers. Therefore, studies that include all oncology decedents have a role. Linkages between cancer registries and administrative databases would allow us to focus on patients who were expected to die of their disease. Finally, there are other aspects of end-of-life care utilization such as clinic and hospice utilization. However, over half of end-of-life oncology costs are known to occur in the inpatient setting in older patients patients (and presumably more in younger patients).¹⁸ Therefore, inpatient costs have important implications for the healthcare system and inpatient utilization may not be consistent with patient wishes. Regardless of the limitations, this study establishes a methodology for studying end-of-life utilization and disparities at a population level and sets a baseline for future studies of AYA oncology end-of-life studies.

In conclusion, this population based study in California revealed that AYA oncology decedents spent an average of 40 days in the hospital in their last year of life – over one in nine days. However, the admissions were not evenly distributed throughout the population with more bed days in Hispanics, younger patients, those with non-HMO insurance, those living further from the hospital, and those with hematologic malignancies. Additionally, the trend over time revealed that those who died after 2003 had increased utilization. It is unknown if these disparities are due to patient preference or another factor such as provider preference or local resources. Additionally, not only are increasing numbers of patients admitted as death approaches, but they are increasingly admitted at non-specialty centers. This has important implications for how AYA end-of-life training and resources are distributed. This study both highlights groups warranting focus for further studies of end-of-life care preferences and lays the groundwork for future studies of end-of-life utilization in this vulnerable population, which will be particularly important to monitor with potential changes to US healthcare policy.

Acknowledgments

Funding: KL2 Mentored Career Development Award (NIH KL2 TR 001083 AND NIH UL1 TR 001085): Johnston salary support

Stanford Center for Policy, Outcomes, and Prevention: data access, programming, and statistical support.

References

- 1. CDC. [accessed October 22, 2015] Ten Leading Causes of Death and Injury. CDC[Report]. 2013. Available from URL: http://www.cdc.gov/injury/wisqars/leadingcauses.html
- Bleyer A. The death burden and end-of-life care intensity among adolescent and young adult patients with cancer. JAMA Oncol. 2015; 1(5):579–580. [PubMed: 26181237]
- 3. Emanuel EJ, Ash A, Yu W, et al. Managed care, hospice use, site of death, and medical expenditures in the last year of life. Arch Intern Med. 2002; 162(15):1722–1728. [PubMed: 12153375]
- Riley GF, Lubitz JD. Long-term trends in Medicare payments in the last year of life. Health Serv Res. 2010; 45(2):565–576. [PubMed: 20148984]
- Center to Advance Pallaitive CAre. Growth of Palliative Care in U.S. Hospitals 2011. CAPC [report]. Available from URL: http://www.hhnmag.com/ext/resources/inc-hhn/pdfs/resources/capcgrowth-analysis-snapshot-2011.pdf
- Benchimol EI, Smeeth L, Guttmann A, et al. The Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. PLoS Med. 2015; 12(10):e1001885. [PubMed: 26440803]
- Healthcare Cost and Utilization Project. [accessed November 3, 2015] Clinical Classification Software - Diagnosis (January 1980 through September 2015). HCUP [Report]. 2014. Available from URL: https://www.hcup-us.ahrq.gov/toolssoftware/ccs/AppendixASingleDX.txt
- Chamberlain LJ, Pineda N, Winestone L, et al. Increased utilization of pediatric specialty care: a population study of pediatric oncology inpatients in california. J Pediatr Hematol Oncol. 2014; 36(2):99–107. [PubMed: 24517965]
- 9. SEER. [accessed November 29, 2015] AYA Site Recode/WHO 2008 Definition.; 2008. SEER [cancer reference information]. 2008. Available from URL: https://seer.cancer.gov/ayarecode/aya-who2008.html
- Elixhauser A, Steiner C, Harris DR, Coffey RM. Comorbidity measures for use with administrative data. Med Care. 1998; 36(1):8–27. [PubMed: 9431328]
- Quan H, Sundararajan V, Halfon P, et al. Coding algorithms for defining comorbidities in ICD-9-CM and ICD-10 administrative data. Med Care. 2005; 43(11):1130–1139. [PubMed: 16224307]
- van Walraven C, Austin PC, Jennings A, Quan H, Forster AJ. A Modification of the Elixhauser Comorbidity Measures into a Point System for Hospital Death Using Administrative Data. Med Care. 2009; 47(6):626–633. [PubMed: 19433995]
- Posey, K. [accessed December 17, 2016] American Community Survey Briefs Household Income: 2015. US Cencus [report]. 2016. Available from URL: http://www.census.gov/content/dam/ Census/library/publications/2016/demo/acsbr15-02.pdf
- Lave JR, Pashos CL, Anderson GF, et al. Costing medical care: using Medicare administrative data. Med Care. 1994; 32(7 Suppl):JS77–89. [PubMed: 8028415]
- 15. Schrag, Deborah. Estimating Inpatient Cancer Care Costs in California: Methodology Detail. California Healthcare Foundation [Report]. 2015. Available from URL: http://www.chcf.org/~/ media/MEDIA%20LIBRARY%20Files/PDF/PDF%20M/PDF %20MethodsInpatientCancerCostsOSHPDLinkCCR.pdf
- Allan DE, Stajduhar KI, Reid RC. The uses of provincial administrative health databases for research on palliative care: Insights from British Columbia, Canada. BMC Palliat Care. 2005; 4(1): 2. [PubMed: 15717923]
- Rosenwax LK, McNamara BA, Murray K, McCabe RJ, Aoun SM, Currow DC. Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. Med J Aust. 2011; 194(11):570–573. [PubMed: 21644868]
- Chastek B, Harley C, Kallich J, Newcomer L, Paoli CJ, Teitelbaum AH. Health care costs for patients with cancer at the end of life. J Oncol Pract Am Soc Clin Oncol. 2012; 8(6):75s–80s.
- Zhang B, Wright AA, Huskamp HA, et al. Health care costs in the last week of life: associations with end-of-life conversations. Arch Intern Med. 2009; 169(5):480–488. [PubMed: 19273778]
- Groff AC, Colla CH, Lee TH. Days Spent at Home A Patient-Centered Goal and Outcome. N Engl J Med. 2016; 375(17):1610–1612. [PubMed: 27783911]

- 21. Au DH, Udris EM, Fihn SD, McDonell MB, Curtis JR. Differences in health care utilization at the end of life among patients with chronic obstructive pulmonary disease and patients with lung cancer. Arch Intern Med. 2006; 166(3):326–331. [PubMed: 16476873]
- 22. Calver J, Bulsara M, Boldy D. In-patient hospital use in the last years of life: a Western Australian population-based study. Aust N Z J Public Health. 2006; 30(2):143–146. [PubMed: 16681335]
- Goodridge D, Lawson J, Duggleby W, Marciniuk D, Rennie D, Stang M. Health care utilization of patients with chronic obstructive pulmonary disease and lung cancer in the last 12 months of life. Respir Med. 2008; 102(6):885–891. [PubMed: 18313278]
- 24. Cintron A, Hamel MB, Davis RB, Burns RB, Phillips RS, McCarthy EP. Hospitalization of hospice patients with cancer. J Palliat Med. 2003; 6(5):757–768. [PubMed: 14622455]
- 25. Gielen B, Remacle A, Mertens R. Patterns of health care use and expenditure during the last 6 months of life in Belgium: differences between age categories in cancer and non-cancer patients. Health Policy Amst Neth. 2010; 97(1):53–61.
- Huang J, Boyd C, Tyldesley S, Zhang-Salomons J, Groome PA, Mackillop WJ. Time spent in hospital in the last six months of life in patients who died of cancer in Ontario. J Clin Oncol Off J Am Soc Clin Oncol. 2002; 20(6):1584–1592.
- 27. Schneider N, Dreier M, Amelung VE, Buser K. Hospital stay frequency and duration of patients with advanced cancer diseases differences between the most frequent tumour diagnoses: a secondary data analysis. Eur J Cancer Care (Engl). 2007; 16(2):172–177. [PubMed: 17371427]
- 28. Levinsky NG, Yu W, Ash A, et al. Influence of age on Medicare expenditures and medical care in the last year of life. JAMA. 2001; 286(11):1349–1355. [PubMed: 11560540]
- 29. Legler A, Bradley EH, Carlson MDA. The effect of comorbidity burden on health care utilization for patients with cancer using hospice. J Palliat Med. 2011; 14(6):751–756. [PubMed: 21548813]
- Johnston EE, Alvarez E, Saynina O, Sanders L, Bhatia S, Chamberlain LJ. End-of-Life Intensity for Adolescents and Young Adults With Cancer: A Californian Population-Based Study That Shows Disparities. J Oncol Pract. 2017; 13(9):e770–e781. [PubMed: 28829692]
- 31. Bureau UC. [accessed February 15, 2016] US Census Data [Reference information]. Available at URL: http://www.census.gov/data.html
- 32. Bach PB, Schrag D, Begg CB. Resurrecting Treatment Histories of Dead Patients: A Study Design That Should Be Laid to Rest. JAMA. 2004; 292(22):2765–2770. [PubMed: 15585737]

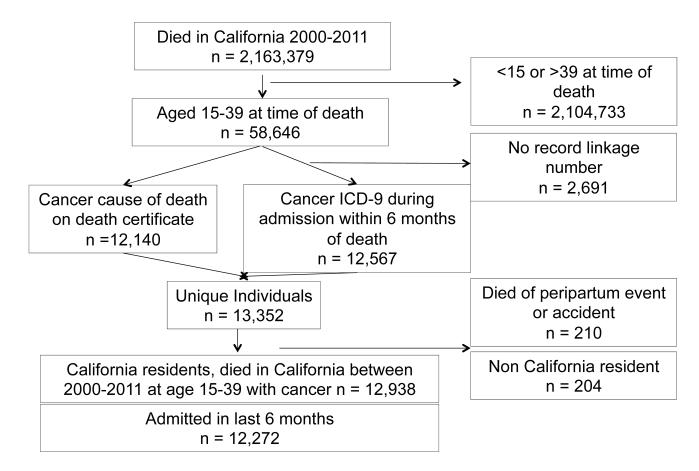
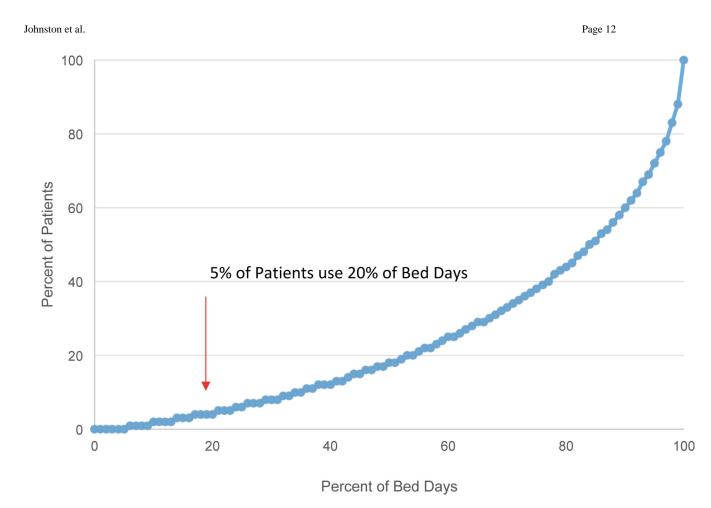
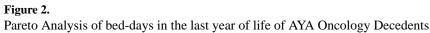


Figure 1.

Study population: Adolescent and Young Adult (15–39) Oncology Decedents in California from 2000 to 2011





Author Manuscript

Johnston et al.

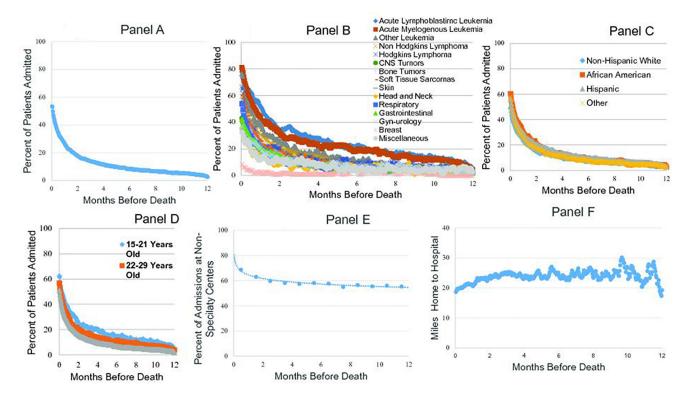


Figure 3.

Patterns of care of AYA oncology descendants in the last year of life: Panel A: Percent of total population admitted each day as death approached, Panel B: By Diagnosis, Panel C: By Race/Ethnicity, Panel D: By Death Age, Panel E: Percent of all admissions at Non-Specialty Centers, Panel F: Distance between hospital and home for patients admitted on a given day before death

Table 1

Demographics and Utilization of Study Population

| DEMOGRAPHI | CS | |
|--|------------------------------|-----------------|
| CHARACTERISTIC | CATETORY | N (%) |
| | | FULL POPULATION |
| | | (12,883 |
| | 15–21 | 1455 (11.3 |
| DEATH AGE | 22–30 | 3088 (24.0 |
| | 31–39 | 8340(64.7 |
| | Not Always Specialty | 9026(70.1 |
| TREATMENT CENTER | Always Specialty | 3195 (24.8 |
| | Not Admitted Last 6 Months | 662 (5.1 |
| | НМО | 1712 (13.3 |
| INSURANCE | Public/Self | 6164 (47.9 |
| | Private | 5003 (38.8 |
| GENDED | Female | 6195 (48.1 |
| GENDER | Male | 6687 (51.9 |
| | Non-Hispanic White | 5948 (46.2 |
| RACE/ETHNICITY | African American | 1170 (9.1 |
| KACE/ETHNICITY | Hispanic | 3883 (30.1 |
| | Other | 1882 (14.6 |
| | Unknown | 238 (1.9 |
| NCOME (In county of residence with reference to Federal Poverty Level) | <2* FPL | 3035 (23.6 |
| (In county of residence with reference to rederar roverty Lever) | 2-4* FPL | 7779 (60.4 |
| | >4 *FPL | 1831 (14.2 |
| METROPOLITAN STATISTICAL AREA | Rural | 857 (6.7 |
| METROFOLITAN STATISTICAL AREA | Urban | 12026 (93.4 |
| | 2000–2003 | 4733 (36.6 |
| YEAR OF DEATH | 2004–2007 | 4436 (34.3 |
| | 2008–2011 | 3769(29.1 |
| | Hematologic Malignancies | 5003 (38.8 |
| | Acute Lymphoblastic Leukemia | 869 (6.8 |
| | Acute Myelogenous Leukemia | 716 (5.6 |
| DIAGNOSIS | Other Leukemia | 297 (2.3 |
| | Non-Hodgkin Lymphoma | 2821 (21.9 |
| | Hodgkin Lymphoma | 300 (2.3 |
| | Solid Tumors | 7880 (61.2 |

| DEMOG | RAPHICS | |
|--------------------------------|---------------------|-----------------------|
| CHARACTERISTIC | CATETORY | N (%) |
| | CNS Tumors | 2639 (20.5) |
| | Bone Tumors | 1407 (10.9) |
| | Soft Tissue Sarcoma | 539 (4.2) |
| | Skin Cancer | 147(1.1) |
| | Head and Neck | 156(1.2) |
| | Respiratory | 943 (7.3) |
| | Gastrointestinal | 1329 (10.3) |
| | Gyn-urology | 410 (3.2) |
| | Breast | 122 (1.0) |
| | Miscellaneous | 192 (1.5) |
| | 0 | 3240 (25.2) |
| COMORBIDITIES AT LAST HOSPITAL | 1 | 3427 (26.6) |
| | 2 or more | 6216 (48.2) |
| | 0–5 miles | 679 (38.0) |
| DISTANCE LAST HOSPITAL TO HOME | 6– 20 miles | 5130 (39.8) |
| | 21 or more miles | 2857 (22.2) |
| | Home | 4211 (32.7) |
| LOCATION DEATH | Hospital | 6814 (52.9) |
| | Other | 1858 (14.4) |
| UTILIZ | ZATION | |
| ASPECT | TIME FRAME | AMOUNT (STD DEV) |
| | Last 6 months | 32 days (34 days) |
| LENGTH OF STAY | Last 12 months | 40 days (42 days) |
| | Last 6 months | \$124,444 (\$175,816) |
| INPATIENT COST | Last 12 months | \$151,072 (\$202,562) |

Author Manuscript

Table 2

Odds of being a top five percent inpatient utilizer in the last year of life for adolescent and young adult oncology patients

Johnston et al.

| CHARACTERIST CATENOR OR Sev. Confidence Interval Parter Parter <th></th> <th></th> <th></th> <th>UN</th> <th>UNADJUSTED</th> <th>ED</th> <th></th> <th>Ida</th> <th>ADJUSTED</th> <th></th> | | | | UN | UNADJUSTED | ED | | Ida | ADJUSTED | |
|---|--------------------|----------------------|------|-----------------|------------------|-----------|------|---------------------|--------------------|---------|
| | CHARACTERISTIC | CATETORY | OR | 95% Coi Inte | nfidence rval | p value | OR | 95 Confi Inte | % dence rval | p value |
| | | 15-21 | 5.13 | 4.19 | 6.29 | <0.0001 | 2.85 | 2.27 | 3.58 | <0.0001 |
| 31-39 REFERENCE Not Always Specially 2.62 2.23 3.09 < 0.0001 1.64 1.36 1.37 Always Specially 2.62 2.23 3.09 < 0.0001 1.64 1.36 2.5 HMO Public/Self 1.81 1.35 2.43 < 0.0001 1.84 1.35 2.5 Public/Self 1.81 1.35 2.43 < 0.0001 1.84 1.35 2.5 Public/Self 1.81 1.35 2.43 < 0.0001 1.48 1.37 2.4 Male 1.34 0.99 1.49 1.66 0.016 1.51 1.23 1.86 Mispanic White 1.14 0.87 1.49 0.96 1.34 1.37 1.37 Mispanic White 1.34 0.99 1.81 0.00 1.41 0.96 1.37 Africian American 1.34 0.99 1.49 0.60 1.36 1.36 Africian American 1.34 0.99 1.41 0.99 0.34 1.36 1.36 Africian American< | DEATH AGE | 22–30 | 2.37 | 1.95 | 2.88 | <0.0001 | 1.81 | 1.48 | 2.22 | <0.0001 |
| Not Always SpeciallyREFERENCEREFERENCEAlways Specially 2.62 3.09 <0.0001 1.64 1.97 Always Specially 2.62 3.09 <0.0001 1.64 1.97 2.04 HMO 1.32 1.35 2.43 <0.0001 1.84 1.97 2.04 Public/Self 1.81 1.35 2.43 <0.0001 1.84 1.07 2.04 Public/Self 1.29 0.94 1.75 0.011 1.48 1.07 2.04 Public/Self 1.29 0.94 1.75 0.0001 1.94 2.04 2.04 Primate 1.24 0.94 1.16 2.35 0.0001 1.16 0.96 1.74 African American 1.34 0.99 1.81 0.0601 1.16 0.96 1.74 African American 1.34 0.99 1.81 0.0601 1.16 0.96 1.74 African American 1.94 0.97 1.94 0.0601 1.94 0.96 1.74 African American 1.94 0.97 1.94 0.0601 1.94 0.96 1.74 African American 1.94 0.98 1.49 0.96 0.74 1.94 1.96 African American 1.94 0.97 1.94 0.96 0.74 1.94 1.96 African American 1.94 0.94 0.94 0.94 0.94 1.94 1.94 African American 1.94 0.94 | | 31–39 | | | | REFERENCE | | | | |
| Always Specialty 2.62 2.22 3.09 <0001 1.64 1.36 1.97 HMO 1.81 1.35 2.43 <0001 1.84 1.35 2.5 PublicSelf 1.81 1.35 2.43 <0001 1.84 1.35 2.9 PublicSelf 1.81 1.35 0.94 1.75 <0001 1.48 1.09 Female 1.29 0.94 1.75 <0001 1.48 1.09 2.04 Non-Hispanic White 1.41 1.19 1.66 <0001 1.15 0.96 1.37 Non-Hispanic White 1.41 1.19 1.66 0.001 1.14 0.96 1.37 African American 1.34 0.99 1.81 0.06 1.24 1.24 0.95 1.24 0.95 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.24 1.2 | TDE ATMENT CENTED | Not Always Specialty | | | | REFERENCE | | | | |
| HMOEFFERENCEMACREFERENCEPublic/Self1.811.352.43<0.0001 | I NEAL WENT CENTER | Always Specialty | 2.62 | 2.22 | 3.09 | <0.0001 | 1.64 | 1.36 | 1.97 | <0.0001 |
| Public/Self1.811.352.43 <0.0001 1.841.352.3Private1.290.941.750.111.481.072.04Female1.411.191.66 <0.0001 1.150.961.37Male1.411.191.66 <0.0001 1.150.961.37Mon-Hispanic White1.340.991.810.0661.240.91.31African American1.340.871.490.061.240.91.36Other1.140.871.490.341.140.861.5Other1.140.871.490.341.140.861.3Var2.4* FPL1.310.991.740.341.140.861.32.4* FPL1.140.871.560.160.910.791.32.4* FPL1.200.931.560.1661.030.791.32.4* FPL1.210.931.560.1661.30.791.32.4* FPL1.200.931.560.1660.761.31.32.4* FPL1.210.931.560.06011.511.31.32.4* FPL1.210.931.560.960.761.31.32.004-072.021.241.642.00011.381.11.72.004-071.621.392.061.392.061.361.311.22.0 | | OMH | | | | REFERENCE | | | | |
| Private1.290.941.750.111.481.072.04Female1.411.191.66<0.0001 | INSURANCE | Public/Self | 1.81 | 1.35 | 2.43 | <0.0001 | 1.84 | 1.35 | 2.5 | <0.0001 |
| FemaleI.15RFFRENCEI.15I.37MaleI.41I.19I.56<0.0001 | | Private | 1.29 | 0.94 | 1.75 | 0.11 | 1.48 | 1.07 | 2,04 | 0.02 |
| Male 1.41 1.19 1.66 <0.0001 1.15 0.96 1.37 Non-Hispanic White 1.34 0.99 1.81 REFERENCE 1.24 0.9 1.71 African American 1.34 0.99 1.81 0.066 1.24 0.9 1.71 Hispanic 1.95 1.62 2.35 <0.0001 1.51 1.28 1.86 Other 1.14 0.87 1.49 0.34 1.14 0.86 1.56 1.56 Other 1.21 0.99 1.74 0.06 0.96 1.56 1.56 2-4* FPL 1.21 0.99 1.74 0.06 0.96 1.3 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-000-03 1.52 1.54 1.86 0.16 1.3 1.11 2-004-07 | | Female | | | | REFERENCE | | | | |
| Non-Hispanic White REFRENCE African American 1.34 0.99 1.81 0.06 1.24 0.9 1.7 Hispanic 1.95 1.62 2.35 <0.0001 | GENDEK | Male | 1.41 | 1.19 | 1.66 | <0.0001 | 1.15 | 0.96 | 1.37 | 0.12 |
| African American 1.34 0.99 1.81 0.06 1.24 0.9 1.7 Hispanic 1.95 1.62 2.35 <0.0001 | | Non-Hispanic White | | | | REFERENCE | | | | |
| Hispanic1.951.622.35<0.00011.511.231.86Other1.140.871.490.341.140.861.5 $<2*FPL$ 1.310.991.740.060.960.791.3 $2-4*FPL$ 1.200.931.560.161.030.791.35 $2-4*FPL$ 1.200.931.560.161.030.791.35 $2-4*FPL$ 1.200.931.740.060.961.361.35 $2-4*FPL$ 1.200.931.560.161.030.791.35 $2-4*FPL$ 1.200.931.560.161.030.791.35 $2-4*FPL$ 1.200.931.560.161.030.791.35 $2-4*FPL$ 1.201.311.990.0601.381.111.72 $200-03$ 1.551.311.99<0.000 | D ACE/ETHNICITV | African American | 1.34 | 0.99 | 1.81 | 0.06 | 1.24 | 0.9 | 1.7 | 0.19 |
| Other 1.14 0.87 1.49 0.34 1.14 0.86 1.5 -2* FPL 1.31 0.99 1.74 0.06 0.96 0.7 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.3 2-4* FPL 1.20 0.93 1.56 0.16 1.3 0.79 1.3 2000-03 1.52 1.24 1.86 0.0001 1.38 1.11 1.72 2004-07 1.52 1.31 1.99 <0.0001 | | Hispanic | 1.95 | 1.62 | 2.35 | <0.0001 | 1.51 | 1.23 | 1.86 | <0.0001 |
| 2* FPL 1.31 0.99 1.74 0.06 0.96 0.7 1.3 $2-4*$ FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.35 $2-4*$ FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.35 $2-4*$ FPL 1.20 0.93 1.56 0.016 1.03 0.79 1.35 $2-4*$ FPL 1.20 1.29 1.56 1.69 1.03 1.35 1.35 $2000-03$ 1.52 1.24 1.86 <0.0001 | | Other | 1.14 | 0.87 | 1.49 | 0.34 | 1.14 | 0.86 | 1.5 | 0.38 |
| 2-4* FPL 1.20 0.93 1.56 0.16 1.03 0.79 1.35 >4 *FPL 1 2 8 8 8 1.10 1.35 2000-03 1.52 1.24 1.86 <0.001 | | <2* FPL | 1.31 | 0.99 | 1.74 | 0.06 | 0.96 | 0.7 | 1.3 | 0.78 |
| >4*FPL REFERENCE 2000-03 REFERENCE 2004-07 1.52 1.24 1.86 <0.0001 | INCOME | 2-4* FPL | 1.20 | 0.93 | 1.56 | 0.16 | 1.03 | 0.79 | 1.35 | 0.81 |
| 2000-03 REFERENCE 2004-07 1.52 1.24 1.86 <0.0001 | | >4 *FPL | | | | REFERENCE | | | | |
| 2004-07 1.52 1.24 1.86 <0.0001 | | 2000–03 | | | | REFERENCE | | | | |
| 2008–11 1.62 1.31 1.99 <0.0001 | YEAR OF DEATH | 2004-07 | 1.52 | 1.24 | 1.86 | <0.0001 | 1.38 | 1.12 | 1.71 | 0.003 |
| Hematologic 4.61 3.83 5.56 <0.0001 3.11 2.56 3.78 Solid Tumors REFERENCE | | 2008-11 | 1.62 | 1.31 | 1.99 | <0.0001 | 1.38 | 1.11 | 1.72 | 0.004 |
| Solid Tumors | STRONG | Hematologic | 4.61 | 3.83 | 5.56 | <0.0001 | 3.11 | 2.56 | 3.78 | <0.0001 |
| | CICONDAID | Solid Tumors | | | | REFERENCE | | | | |

| Auth |
|--------|
| ior Ma |
| anusc |
| cript |

Author Manuscript

Johnston et al.

Author Manuscript

| | | | NN | UNADJUSTED | D | | ADJ | ADJUSTED | |
|--------------------------------|-----------|------|-------------------------|----------------------------|-----------|------|------------------------------|-------------------------------|---------|
| CHARACTERISTIC | CATETORY | OR | 95% Confide Interval | 95% Confidence Interval | p value | OR | 95% Confidenc Interval | 95% Confidence Interval | p value |
| | 0 | | | | REFERENCE | | | | |
| COMORBIDITIES AT LAST HOSPITAL | 1 | 1.40 | 1.06 | 1.86 | 0.02 | 1.13 | 1.13 0.84 1.51 | 1.51 | 0.43 |
| | 2 or more | 2.36 | 1.85 | 3.02 | <0.0001 | 1.49 | 1.49 1.15 1.93 | 1.93 | 0.003 |
| | 0–5 miles | | | | REFERENCE | | | | |
| DISTANCE LAST HOSPITAL TO HOME | 6– 20 mi | 1.58 | 1.29 | 1.94 | <0.0001 | 1.27 | 1.27 1.03 1.58 | 1.58 | 0.03 |
| | 21 mi | 2.63 | 2.12 | 3.25 | <0.0001 | 1.72 | 1.72 1.36 | 2.17 | <0.0001 |
| | Home | | | | REFERENCE | | | | |
| LOCATION DEATH | Hospital | 4.44 | 3.42 | 5.77 | <0.0001 | 3.02 | 2.3 | 3.96 | <0.0001 |
| | Other | 1.55 | 1.05 | 2.26 | 0.03 | 1.56 | 1.56 1.06 2.3 | 2.3 | 0.03 |
| | | | | | | | | | |