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End-of-Life Transitions and Hospice Utilization for Adolescents: Does Having a Usual Source of Care Matter?

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Abstract

Adolescents with life-limiting illnesses have intensive end-of-life trajectories and could benefit from initiation of hospice services. The medical home model, which includes having a usual source of primary care, may help facilitate quality outcomes at the end-of-life for adolescents. The purpose of this study was to determine the relationship between having a usual source of primary care on hospice utilization and end-of-life transitions among adolescents between 15–20 years with a life-limiting illness. A retrospective cohort design used 2007–2010 California Medicaid claims data (n=585). Our dependent variables were hospice utilization (i.e., hospice enrollment, hospice length of stay) and the independent variable was usual source of primary care.

Multivariate regression techniques including least squares regression, multivariate logistic regression, and negative binomial regression were used in the analysis of the relationship between usual source of primary care and hospice utilization and end-of-life transitions. Ten percent of our sample utilized hospice services. Having a usual source of primary care was associated with an increase in hospice enrollment, hospice length of stay, and end-of-life transitions. Adolescents with a cancer diagnosis were more likely to enroll in hospice services. For adolescents at the end of life, having a usual source of primary care had a significant impact on hospice enrollment and length of stay. This study is among the first to demonstrate a relationship between primary care and hospice use among this vulnerable population.

Keywords

pediatric; hospice; adolescent; transition; end-of-life

Introduction

Nearly 27,000 youth between the ages of 10 to 24 years die each year in the United States.¹ As many as 4000 deaths among adolescents are attributed to serious, life-limiting health conditions.² There is very little empirical knowledge pertaining to end-of-life care

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trajectories for adolescents with life-limiting conditions. Adolescents are at risk for receiving fragmented care as they are caught between the worlds of pediatric and adult providers, as well as between primary care and numerous specialist providers. Meanwhile, the number of youth with life-limiting conditions is increasing, and determining appropriate end-of-life care transitions (meaning transitions between multiple care providers and environments of care) can be particularly challenging secondary to the increased intensity of service provision and clinical uncertainty that occur during the time period preceding death.³⁻⁶ Thus, adolescents represent a particularly vulnerable population at the end of life.

What we do know about caring for adolescents at end of life is limited. Nearly three-fourths of young people who die do so in an acute or intensive care setting without comprehensive palliative or hospice care management and are at risk for numerous burdensome transitions between multiple providers at the end of life.^{3,5,7-11} To this end, the holistic model of care that hospice provides represents an opportunity for patient- and family-centered end-of-life care for young people.¹²⁻¹⁴ Hospice care offers a comprehensive approach to end of life for those with life expectancy of 6 months or less, which incorporates symptom management, psychosocial and spiritual needs, life review, and continued goal setting.¹² From a developmental perspective, adolescents at the end of life are at particular risk for anticipatory grief and changes in peer relationships, which can make elements of life review and existential processing even more critical.^{6,15,16} Literature also suggests that they have numerous unrelenting symptoms at the end-of-life such as pain, fatigue, and sleep disturbances.¹⁷ There are several documented barriers to hospice utilization for young people, but it is known that quality communication with care teams and early goals of care discussion can help foster hospice enrollment.^{12,18-20}

Continuous primary care is a central tenet of the medical home model, and for those with life-limiting illnesses, primary care providers are often key to comprehensive communication between specialists as well as fostering goals of care discussions.^{21,22} Preliminary work in this area suggests that, compared to other pediatric age groups, adolescents are most influenced by their relationship with a primary care provider.²³ However, a major concern among adolescents is aging out of service with their usual source of primary care. Many pediatricians, for example, require adolescents to find a family practice or internal medicine provider once they reach 18 or 19 years of age, which often disrupts the trusted relationship that has formed between the adolescent and provider over the youth's lifetime. We posit that having a usual source of primary care would help foster hospice utilization and reduce end-of-life transitions among adolescents with life-limiting illness. Therefore, the purpose of this paper is to elucidate the relationship between a usual source of primary care and end-of-life care delivered to adolescents (including hospice utilization and end-of-life transitions).

Conceptual Model

The conceptual foundation for this study is based on a modification of the Andersen Behavioral Healthcare Utilization Model,¹³ which explains why individuals use health services.²⁴ Central to the Andersen model is the notion that health care utilization is a result of predisposing factors that are family-centric, enabling factors that either promote or

impede use, and the underlying need for service utilization.²⁴ For this study, a critical enabling factor among adolescents at end of life was conceptualized as a usual source of primary care, while health care utilization was conceptualized as hospice utilization and end-of-life transitions. From the perspective of the Anderson Model, a usual source of primary care may enable adolescents utilize hospice care and reduce end-of-life transitions through care coordination and navigation as they work with adolescents and their families to ensure quality care at end of life. Thus, we hypothesized that usual source of primary care would influence hospice utilization and end-of-life transitions.

Our covariates in the model, were also guided by the Anderson Model. Predisposing factors of end-of-life service transitions and hospice utilization include demographics such as: (1) gender,^{25,26} (2) race,^{25,27} and (3) ethnicity.²⁷ Enabling factors include: (1) concurrent private insurance,²⁷ and (2) case management.¹⁸ Need for health services includes: (1) health condition (cancer, neurological and cardiovascular etiologies), and (2) co-morbidities, both of which may impact the likelihood that the serious illness offers the ability to prognosticate and the amount of burdensome symptoms.²⁷ Thus, our research question and variable definitions were guided by predisposing, enabling, and need factors that have the potential to affect transitions and hospice use among adolescents with life-limiting illness.

Methods

Design and Sample

This study was a retrospective cohort design examining the relationship between usual source of care and end-of-life transitions and hospice utilization. Adolescents were included if their age at death was between the ages of 15 and 20 years, they died between January 1, 2007 and December 31, 2010 based on the Social Security date of death, were enrolled in the California Medicaid program for any part of their last calendar year of life, and had a diagnosis of a complex chronic condition based on the *International Classification of Diseases, 9th revision* (ICD-9) code as recommended by Feudtner and colleagues.²⁸ Adolescents were excluded if they had missing entries in study variables, were not California residents. In addition, adolescents that participated in Medicaid managed care plans were excluded because their claims data were not included in the Medicaid data files. The selected sample consisted of 585 adolescents. Our study was approved by the Institutional Review Board at the University of Tennessee, Knoxville.

Data Sources

Data were retrieved from the California Medicaid claims files (Medicaid Analytic Extract [MAX]), 2007–2010. We used the Medicaid Person Summary file for enrollment and demographic information, and the MAX Other Services files for procedure codes (CPT), for hospice care services and ICD-9 diagnosis codes. Medicaid claims data were used because they include transitions and hospice utilization information. California was chosen for this study because it has the largest population of adolescents enrolled in Medicaid of any state.²⁹

Measures

Dependent variables—Three measures of end-of-life transitions and hospice utilization (hospice enrollment and hospice length of stay) were developed for this study. The first measure, *end-of-life transitions*, was the sum of inpatient stays, outpatient visits, and clinic visits divided by the number of months the adolescent was enrolled in Medicaid during the last calendar year of life.^{10,30–34} The second measure, *hospice enrollment*, was defined as whether or not the adolescent enrolled in outpatient hospice care during the last calendar year of life.^{23,35} This variable was created using data from the MAX Personal Summary Record type with service indicator code 35 for hospice and confirmed in the MAX Other Services Record using revenue codes 651, 652, 655, and 656. The third measure, *hospice length of stay*, was operationalized as a daily count of outpatient hospice care encounters in the last year of life.³⁶ Daily counts of hospice length of stay were derived from the per diem payments to hospice using the MAX Other Services hospice revenue codes.

Independent variable—Usual source of care was operationalized as whether the adolescent was an established patient with an identified primary care provider during the last year of life.^{23,37}

Covariates—Predisposing characteristics of the adolescents were *gender*, *race*, and *ethnicity*. Gender was defined as male or female. Race was categorized as Caucasian or non-Caucasian and ethnicity was Hispanic or non-Hispanic. Enabling characteristics included *private insurance* and *case management*. Whether or not the adolescent had private health insurance in addition to Medicaid was the measure of private insurance. Case management was categorized as having an assigned Medicaid case manager or not. Need characteristics were diagnoses (*cancer*, *neurological*, *cardiovascular*), and *co-morbidities*. Separate variables were created for the complex chronic conditions cancer, neurological (i.e., brain and spinal cord malformation, moderate and severe intellectual disabilities, cerebral palsy, epilepsy, muscular dystrophies), and cardiovascular (i.e., heart and valve malformations, cardiomyopathies, conduction disorders). Comorbidities were defined as having two or more complex chronic conditions.

Data Analysis

Descriptive statistics were calculated for adolescents in the sample using pooled, cross-sectional data. Separate multivariate analyses with year fixed effects were conducted for end-of-life transitions, hospice enrollment, and hospice length of stay. Year fixed effects with year variables were included to control for time specific effects in the model because we used longitudinal data. First, we modeled the effect of usual source of care on end-of-life transition rate using an ordinary least squares regression analysis and reported the results as β coefficients. Second, we used a multivariate logistic regression to examine the effect of usual source of care on hospice enrollment, which was reported as adjusted odds ratios (OR).³⁸ Third, a negative binomial model was used to explore the relationship between usual source of care and hospice length of stay.³³ The negative binomial results were reported as adjusted incidence rate ratios (IRR). All analyses were conducted using Stata 11.0 (StataCorp LP, College Station, TX).

Results

Participant characteristics

Sample characteristics are presented in Table 1. Nearly 67% of the sample had a usual source of primary care. More than half of the sample were male (57%), and non-Caucasian (74%); a small subset had additional private insurance (16%). A third of the adolescents (33%) had a case manager involved in Medicaid service provision. About half of the sample had a neurological diagnosis (51%), with cancer and cardiovascular etiologies following in equal percentages (37%). Not surprisingly, 41% had two or more chronic, complex conditions. Adolescents averaged nearly 3 transitions in their last year of life (range 0 to 36 transitions). Only 10% enrolled in hospice prior to their death with a mean hospice length of stay of 1.77 days.

Multivariate analysis

End-of-life transitions—After controlling for covariates, results of the relationship between usual source of care and end-of-life transitions are found in Table 2. Adolescents having a usual source of primary care in the last year of life were associated with a statistically significant increase in end-of-life care transitions ($\beta = 1.68$, $p < 0.001$), compared to adolescents without a usual source of care. A diagnosis of cancer contributed to a statistically significant increase in end-of-life transitions ($\beta = 2.81$, $p < 0.001$). No other covariates in the model were significantly related to end-of-life transitions.

Hospice utilization—Results from the regression analysis assessing usual source of care on hospice enrollment and hospice length of stay are found in Table 3. Youth with a usual source of care had a statistically significant increased odds of enrollment in hospice care (OR = 4.07, CI = 1.732–9.577) with longer hospice lengths of stay (IRR = 6.09, CI = 1.480–25.096). Adolescents with a diagnosis of cancer were roughly three and a half times as likely to enroll in hospice (OR = 3.59, CI = 1.544–8.386) with longer hospice lengths of stay (IRR = 9.47, CI = 2.284–39.303). Females (IRR = 0.22, CI = 0.073–0.689) and adolescents with a cardiovascular condition (IRR = 0.18, CI = 0.042–0.729) had statistically significant shorter hospice lengths of stay. Additionally, those who died in 2008 were significantly less likely to enroll in hospice (OR 0.30, CI = 0.124–0.738), compared those who died in 2007. No other covariates were independently associated with hospice enrollment or length of stay.

Discussion

The goal of the study was to examine the relationship between usual source of care and end-of-life transitions and hospice utilization. Over two-thirds of the adolescents included in this study had a usual source of primary care. Adolescents averaged approximately 2 visits with their usual source of primary care in their last year of life (data not shown). It was common for youth to average nearly 3 transitions between providers during the last year of life. Furthermore, only 10% of the sample were ever enrolled in hospice care; and the length of stay for those few was less than 2 days. By comparison, it is estimated that a third of all adult Medicare decedents access hospice services at the end-of-life.³⁹ Other, related work has shown hospice enrollment for children ranges from 15–26%.^{36,40}

Primary health care providers may be a key for attaining comprehensive patient-centered care at the end of life, and maintaining a usual source of primary care can serve as a medical home during serious illness.⁴¹ While there are many benefits of a medical home for young people with chronic and life-limiting conditions,⁴² an unintended consequence may be increased service utilization as demonstrated by the rise in end-of-life transitions to acute and ambulatory settings. Data did not support the premise that having a usual source of care would decrease end-of-life transitions for adolescents. Changes in available therapeutics and technology have created a historical shift to allow for intensive medical regimens and an uptake in burdensome transitions prior to the end of life.^{8,10,11} One potential explanation is that those with the most intense medical regimens, symptom experience, and subsequent service utilization were more likely to maintain contact with their primary care provider, hence we cannot rule out reverse causation. Further longitudinal study is warranted to elucidate end-of-life care trajectories for adolescents and to determine the temporal impact of primary care involvement on transitions at the end of life.

This study provides novel data and its findings support that having a usual source of primary care within the last year of life is associated both with increased utilization of hospice and end-of-life transitions. Previous reports have demonstrated that many states have a robust network of primary care practitioners to offer additional support to Medicaid patients with chronic illnesses,^{18,23,36,43} so it is not surprising that this trend would also be evident among those with life-limiting diagnoses. Primary care providers may be able to offer an additional layer of support through comprehensive symptom-based management, spiritual assessments, discussions surrounding goals of care, and advance care planning (ACP).⁴⁴ Previous research suggests that older children with routine access to primary care may have long-standing relationships with those providers, and leveraging the trust inherent in those relationships may help young people engage in end-of-life discussions.⁴⁵ Furthermore, allowing adolescents to actively participate in goals of care and ACP discussions may lead to an uptake in hospice services.⁴⁶

Another interesting finding was that adolescents with a cancer diagnosis were more likely to use hospice than those with a non-cancer diagnosis. This trend is pervasive among older adults as well,³⁹ and is also supported by previous pediatric data due in large part to the fact that malignancies are the leading non-accidental cause of death in the adolescent population.^{1,8,47} Aside from epidemiologic trends, it is likely that a cancer diagnosis may offer a more concrete ability to prognosticate compared to non-cancer etiologies, which is imperative for hospice enrollment.⁴⁸ Despite this, the ability to offer a 6 month or less life expectancy is cited as a primary barrier to hospice enrollment, particularly among children, where it is generally much more difficult to offer families a prognosis estimate and facilitate a therapeutic conversation focused on prognosis compared to adults.^{12,49,50} Although our data did not permit an examination of specific cancer diagnosis and their relation to end-of-life care, future research exploring the different cancer types is warranted.

There are several current policy considerations that will likely impact transitions and hospice utilization. Under the Patient Protection and Affordable Care Act (ACA), accountable care organizations (ACOs) will be the predominant mechanism for ensuring high-quality patient outcomes at prospective per-capita costs, particularly for those children enrolled in

Medicaid.^{48–50} Many ACOs will be operationalized as treatment provided in a patient-centered medical home. Additionally, many states now have the option of pursuing Medicaid managed care models for the long-term care needs of patient populations with chronic illness. However, advocates in this community are concerned that these policy shifts will vastly destabilize the already limited access to home-and-community-based services, including hospice.⁵⁴ To this end, coordination of primary care providers with specialists, and maintenance of a patient-centered medical home, will be central to integrated and high quality care delivery for people with life-limiting and life-threatening conditions. A much needed area of future inquiry focuses on the impact of ACOs on hospice utilization for young people.

Several limitations in this study merit comment. Even though the ‘usual source of care’ was operationalized in ways similar to previous research endeavors,²³ there is a chance that this variable did not capture all sources of usual care, for example, nurse coordination. There is potential selection bias for the use of the California Medicaid database, which only includes children enrolled in fee-for-service Medicaid and CHIP, and not Medicaid managed care models. Because of this sample, findings may not be generalizable to adolescents who reside outside of California or have private insurance only. Additionally, our analysis was pooled, cross-sectional in nature and limited to the last year of life of the adolescent, which highlights the need for future research involving panel data studies that precede the last year of life. There may have been other confounding variables associated with hospice that could not be appreciated using this data set. Another limitation was that the data in our analysis was truncated which is defined as incomplete data because a systematic selection process. For our study, the systematic selection process was that only adolescents in the that last year of life were included. As a result, an adolescent might have hospice claims in the prior year. We evaluated the extent that our data were truncated and potentially biased, and found that less than 0.5% of the adolescents may have had claims in the prior year. Thus, we did not model truncation as part of the analysis plan. Finally, our adolescent population was limited to those between the ages of 15 and 20, due in part to the Medicaid eligibility differences in those ages 21 and older. Even so, using the California Medicaid data offers a vital and novel contribution to the literature using a comprehensive claims database for adolescents at the end of life.

Conclusions

For adolescents at the end of life, we observed a significant impact of having a usual source of primary care on end-of-life transitions and hospice enrollment and length of stay. To the authors’ knowledge, this study is the first to demonstrate a relationship between primary care transitions and end-of-life care outcomes among this adolescent population. Adolescents with life-limiting illness are particularly at risk for fragmented care delivery due to the fact that they are experiencing serious illness coupled with the ‘aging out’ of pediatric providers and transition to adult services. The findings also reflect an overall diminished utilization of hospice when compared to other age groups, according to the literature. Very little is known about adolescents’ end-of-life care trajectories and there is a paucity of research assessing: (1) longitudinal changes and the impact of earlier hospice initiation for this unique age group, (2) potential relationship of routine access to primary care providers,

access to the patient-centered medical home, and service coordination, and (3) policy provisions from the ACA that have the potential to impact access to hospice. Our results suggest that primary care providers may have a profound role in improving quality end-of-life outcomes for adolescents with life-limiting diagnoses.

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References

- Osterman MJK, Kochanek KD, MacDorman MF, Strobino DM, Guyer B. Annual Summary of Vital Statistics: 2012–2013. *Pediatrics*. 2015; 135(6):1115–1125. DOI: 10.1542/peds.2015-0434 [PubMed: 25941306]
- [Accessed July 5, 2016] 10 Leading causes of death by age. http://www.cdc.gov/injury/wisqars/pdf/leading_causes_of_death_by_age_group_2014-a.pdf
- Mack J, Chen K, Boscoe F, et al. High intensity of end-of-life care among adolescent and young adult cancer patients in the New York State Medicaid program. *Med Care*. 2015; 53(12):1018–1026. DOI: 10.1097/MLR.0000000000000437 [PubMed: 26492211]
- 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(5):592–600. DOI: 10.1001/jamaoncol.2015.1953 [PubMed: 26181778]
- Erickson JM, Malpass HC. End-of-Life Care Characteristics for Young Adults with Cancer Who Die in the Hospital. *J Palliat Med*. 2014; 17(12):1359–1364. Author1. DOI: 10.1089/jpm.2013.0661 [PubMed: 24964075]
- Adelstein K, Kavalieratos D. Legacy Making Through Illness Blogs: Online Spaces for Young Adults Approaching the End-of-Life. *J Adolesc Young Adult Oncol*. 2015; 4(4):209–212. Author1. <http://dx.doi.org/10.1089/jayao.2015.0003>. [PubMed: 26697270]
- Davies B, Sehring SA, Partridge JC, et al. Barriers to palliative care for children: perceptions of pediatric health care providers. *Pediatrics*. 2008; 121(2):282–288. DOI: 10.1542/peds.2006-3153 [PubMed: 18245419]
- Friebert, S. NHPCO Facts and Figures: Pediatric Palliative and Hospice Care in America. 2009. http://www.nhpco.org/files/public/quality/Pediatric_Facts-Figures.pdf
- Bradshaw G, Hinds PS, Lensing S, Gattuso JS, Razzouk BI. Cancer-related deaths in children and adolescents. *J Palliat Med*. 2005; 8(1):86–95. DOI: 10.1089/jpm.2005.8.86 [PubMed: 15662177]
- Teno JM, Gozalo PL, Bynum JPW, et al. Change in End-of-Life Care for Medicare Beneficiaries. *JAMA*. 2014; 309(5):470–477. DOI: 10.1001/jama.2012.207624.Change
- Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med*. 2011; 365(13):1212–1221. DOI: 10.1056/NEJMs1100347 [PubMed: 21991894]
- Field, MJ., Behrman, RE. *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*. Washington, D.C: National Academies Press; 2003.
- Determinants of Access to Pediatric Hospice Care. *J Hosp Palliat Nurs*. 2015; 17:113–118. Author2. DOI: 10.1097/NJH.0000000000000132 [PubMed: 25983662]
- Knapp CA. Research in pediatric palliative care: closing the gap between what is and is not known. *Am J Hosp Palliat Care*. 2009; 26(5):392–398. DOI: 10.1177/1049909109345147 [PubMed: 19745209]

15. Stegenga K, Loudin B, Kennedy C, Kools S. "It's Back! My Remission Is Over": Online Communication of Disease Progression Among Adolescents With Cancer. *J Pediatr Oncol Nurs*. 2016; 33(3):209–217. Author1. DOI: 10.1177/1043454215600424 [PubMed: 26483425]
16. Steeves RH. Talking With Death at a Diner: Young Women's Online Narratives of Cancer. *Oncol Nurs Forum*. 2012; 39(4):373–378. Author1. DOI: 10.1188/12.ONF.373-378 [PubMed: 22750895]
17. Kestler SA, LoBiondo-Wood G. Review of symptom experiences in children and adolescents with cancer. *Cancer Nursing*. 2012; 35(2):E31–49. DOI: 10.1097/NCC.0b013e3182207a2a [PubMed: 21760492]
18. Beyea A, Fischer J, Schenck A, Hanson LC. Integrating palliative care information and hospice referral in medicaid primary care. *J Palliat Med*. 2013; 16(4):376–382. DOI: 10.1089/jpm.2012.0483 [PubMed: 23461299]
19. Ullrich CK, Lehmann L, London WB, et al. End-of-Life Care Patterns Associated with Pediatric Palliative Care among Children Who Underwent Hematopoietic Stem Cell Transplant. *Biol Blood Marrow Transplant*. 2016; 22(6):1049–1055. DOI: 10.1016/j.bbmt.2016.02.012 [PubMed: 26903381]
20. Dickens D. Comparing Pediatric Deaths With and Without Hospice Support. *Pediatr Blood Cancer*. 2010; 54:746–750. DOI: 10.1002/pbc [PubMed: 20063424]
21. Tripathi SS, Cantwell GP, Ofir A, Serrecchia D, Peck S. Pediatric palliative care in the medical home. *Pediatr Ann*. 2012; 41(3):112–116. DOI: 10.3928/00904481-20120206-11 [PubMed: 22420385]
22. Sanderson A, Hall AM, Wolfe J. Advance Care Discussions: Pediatric Clinician Preparedness and Practices. *J Pain Symptom Manage*. 2016; 51(3):520–528. DOI: 10.1016/j.jpainsymman.2015.10.014 [PubMed: 26550935]
23. Nageswaran S. Pediatric Primary Care Involvement in End-of-Life Care for Children. *Am J Hosp Palliat Med*. 2015; Author2. doi: 10.1177/1049909115609589
24. Andersen R, Newman JF. Societal and individual determinants of medical care utilization in the United States. *Milbank Mem Fund Q Health Soc*. 1973; 51(1):95–124. <http://www.ncbi.nlm.nih.gov/pubmed/4198894>. [PubMed: 4198894]
25. Mack JW, Chen K, Boscoe FP, et al. Underuse of hospice care by Medicaid-insured patients with stage IV lung cancer in New York and California. *J Clin Oncol*. 2013; 31(20):2569–2579. DOI: 10.1200/JCO.2012.45.9271 [PubMed: 23733768]
26. Knapp CA, Thompson La, Vogel WB, Madden VL, Shenkman Ea. Developing a pediatric palliative care program: addressing the lack of baseline expenditure information. *Am J Hosp Palliat Care*. 2009; 26(1):40–46. DOI: 10.1177/1049909108327025 [PubMed: 19047489]
27. Linton JM, Feudtner C. What accounts for differences or disparities in pediatric palliative and end-of-life care? A systematic review focusing on possible multilevel mechanisms. *Pediatrics*. 2008; 122(3):574–582. DOI: 10.1542/peds.2007-3042 [PubMed: 18762528]
28. Feudtner C, Hays RM, Haynes G, Geyer JR, Neff JM, Koepsell TD. Deaths attributed to pediatric complex chronic conditions: national trends and implications for supportive care services. *Pediatrics*. 2001; 107(6):E99. doi: 10.1542/peds.107.6.e99 [PubMed: 11389297]
29. Total Monthly Medicaid and CHIP Enrollment. Kaiser Family Foundation; <http://kff.org/health-reform/state-indicator/total-monthly-medicaid-and-chip-enrollment/>. Published 2016 [Accessed July 20, 2016]
30. Wang SY, Aldridge MD, Gross CP, et al. Transitions between healthcare settings of hospice enrollees at the end of life. *J Am Geriatr Soc*. 2016; 64(2):314–322. DOI: 10.1111/jgs.13939 [PubMed: 26889841]
31. Teno JM, Mitchell SL, Skinner J, et al. Churning: the association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *J Palliat Med*. 2009; 12(4):359–362. DOI: 10.1089/jpm.2008.0168 [PubMed: 19327073]
32. Teno JM, Plotzke M, Gozalo P, Mor V. A National Study of Live Discharges from Hospice. *J Palliat Med*. 2014; 17(10):4–10. DOI: 10.1089/jpm.2013.0595 [PubMed: 24286202]
33. Prisc E, Pltozke M, Christian TJ, Gozalo P, Teno JM. A National Study of Live Hospice Discharges Between 2000 and 2012. *J Palliat Med*. 2016; XX Xx jpm.2015.0383. doi: 10.1089/jpm.2015.0383

34. Trask PC, Teno JM, Nash J. Transitions of Care and Changes in Distressing Pain. *J Pain Symptom Manage*. 2006; 32(2):104–109. DOI: 10.1016/j.jpainsymman.2006.03.007 [PubMed: 16877177]
35. Shaw S-L. Who are the children using hospice care? *J Spec Pediatr Nurs*. 2014; 19(4):308–315. 8. Author2. DOI: 10.1111/jspn.12085 [PubMed: 25131751]
36. Newnam KM. Hospice Use for Infants With Life-Threatening Health Conditions, 2007 to 2010. *J Pediatr Heal Care*. 2016; :1–8. Author2. DOI: 10.1016/j.pedhc.2016.04.015
37. Perrin J, Greenspan P, Bloom S, et al. Primary care involvement among hospitalized children. *Arch Pediatr Adolesc Med*. 1996; 150(5):479–486. [PubMed: 8620228]
38. Long, J., Freese, J. STATA Press Publications. *Regression Models for Categorical Dependent Variables Using Stata*. College Station, TX: 2014.
39. Organization NH and PC. [Accessed June 28, 2016] NHPCO's Facts and Figures: Hospice Care in America. http://www.nhpc.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf. Published 2015
40. Lyon ME. A profile of children with complex chronic conditions at end of life among Medicaid beneficiaries: implications for health care reform. *J Palliat Med*. 2013; 16(11):1388–1393. Author2. DOI: 10.1089/jpm.2013.0099 [PubMed: 24102460]
41. Knapp C, Baker K, Cunningham C, Downing J, Fowler-Kerry S, McNamara K. Pediatric palliative care and the medical home. *J Palliat Med*. 2012; 15(6):643–645. DOI: 10.1089/jpm.2012.0075 [PubMed: 22656054]
42. Willits KA, Platonova Ea, Nies Ma, Racine EF, Troutman ML, Harris HL. Medical home and pediatric primary care utilization among children with special health care needs. *J Pediatr Health Care*. 2013; 27(3):202–208. DOI: 10.1016/j.pedhc.2011.11.004 [PubMed: 22243921]
43. Mixer S, Mack J. Home care for children with multiple complex chronic conditions at the end of life: The choice of hospice versus home health. *Home Heal Care Serv Q*. 2016 Jul.:1–11. Author2.
44. Ghosh A, Dzung E, Cheng MJ. Interaction of palliative care and primary care. *Clin Geriatr Med*. 2015; 31(2):207–218. DOI: 10.1016/j.cger.2015.01.001 [PubMed: 25920056]
45. Wiener L, Ballard E, Brennan T, Battles H, Martinez P, Pao M. How I wish to be remembered: the use of an advance care planning document in adolescent and young adult populations. *J Palliat Med*. 2008; 11(10):1309–1313. DOI: 10.1089/jpm.2008.0126 [PubMed: 19115889]
46. Wiener L, Zadeh S, Battles H, et al. Allowing adolescents and young adults to plan their end-of-life care. *Pediatrics*. 2012; 130(5):897–905. DOI: 10.1542/peds.2012-0663 [PubMed: 23045560]
47. Johnston DL, Nagel K, Friedman DL, Meza JL, Hurwitz Ca, Frieberst S. Availability and use of palliative care and end-of-life services for pediatric oncology patients. *J Clin Oncol*. 2008; 26(28):4646–4650. DOI: 10.1200/JCO.2008.16.1562 [PubMed: 18824711]
48. Catalyst Center. Financing Pediatric Palliative and Hospice Care Programs. 2011. hdwg.org/sites/default/files/palliativecare.pdf
49. Wolfe J, Klar N, Grier HE, et al. Understanding of prognosis among parents of children who died of cancer: impact on treatment goals and integration of palliative care. *JAMA*. 2000; 284(19):2469–2475. DOI: 10.1001/jama.284.19.2469 [PubMed: 11074776]
50. Rosenberg AR, Orellana L, Kang TI, et al. Differences in parent-provider concordance regarding prognosis and goals of care among children with advanced cancer. *J Clin Oncol*. 2014; 32(27):3005–3011. DOI: 10.1200/JCO.2014.55.4659 [PubMed: 25024073]
51. Sharma N, O'Hare K, Antonelli R, Sawicki G. Transition care: future directions in education, health policy, and outcomes research. *Acad Pediatr*. 2014; 14(2):120–127. DOI: 10.1016/j.acap.2013.11.007 [PubMed: 24602574]
52. Longworth DL. Accountable care organizations, the patient-centered medical home, and health care reform: what does it all mean? *Cleve Clin J Med*. 2011; 78(9):571–582. DOI: 10.3949/ccjm.78gr.11003 [PubMed: 21885689]
53. Hall AG, Landry AY, Lemak CH, Boyle EL, Duncan RP. Reported Experiences with Medicaid Managed Care Models Among Parents of Children. *Matern Child Health J*. Apr.2013 doi: 10.1007/s10995-013-1270-5
54. Ostrov, B., Gorman, A. [Accessed August 18, 2015] California's Plan to Absorb Medically Fragile Children Into Managed Care Proves Controversial. *Kaiser Health News*. <http://khn.org/news/>

[californias-plan-to-absorb-medically-fragile-children-into-managed-care-proves-controversial/](#).
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Table 1

Descriptive Statistics of Study Variables (N=585)

Variables	N	Percentage/Mean (SD)
Dependent Variables		
End-of-life Transitions	585	2.72 (4.57)
Hospice Utilization		
Hospice Enrollment	58	10.0%
Hospice Length of Stay	585	1.77 (10.15)
Independent Variable		
Usual Source of Care	389	66.5%
Covariates		
Gender		
Male	334	57.1%
Female	251	42.9%
Race		
Caucasian	154	26.3%
Non-Caucasian	431	73.7%
Ethnicity		
Private Insurance	92	15.7%
Case Management	191	32.7%
Diagnosis		
Cancer	216	36.9%
Neurological	299	51.1%
Cardiovascular	216	36.9%
Co-Morbidities		
Year 2007	142	24.3%
Year 2008	145	24.8%
Year 2009	160	27.4%
Year 2010	138	23.6%

Table 2

Results of Regression for End-of-Life Transitions (N=585)

Variables	β	95% CI
Independent Variable		
Usual Source of Care	1.68***	0.900–2.456
Covariates		
Female	–0.03	–0.725–0.662
Caucasian	0.20	–0.721–1.123
Ethnicity	0.04	–0.780–0.852
Private Insurance	–0.97	–1.967–0.025
Case Management	–0.74	–1.590–0.118
Cancer	2.81***	1.823–3.790
Neurological	–0.15	–1.084–0.785
Cardiovascular	0.86	–0.094–1.821
Co-Morbidities	0.29	–0.667–1.245
Year 2008	–0.28	–1.243–0.689
Year 2009	0.84	–0.102–1.786
Year 2010	0.31	–0.674–1.290

*
 $p < 0.05$,**
 $p < 0.01$,***
 $p < 0.001$

Note: CI, Confidence Intervals.

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Table 3

Results of Regressions for Hospice Utilization (N=585)

Variables	Hospice Enrollment		Hospice Length of Stay	
	OR	95% CI	IRR	95%CI
Independent Variable				
Usual Source of Care	4.07 ^{***}	1.732–9.577	6.09 [*]	1.480–25.096
Covariates				
Female	0.81	0.443–1.464	0.22 ^{**}	0.073–0.689
Caucasian	1.95	0.885–4.310	3.84	0.661–22.339
Ethnicity	0.97	0.458–2.053	1.41	0.332–5.988
Private Insurance	0.61	0.222–1.691	1.92	0.240–15.399
Case Management	0.78	0.367–1.660	0.32	0.070–1.457
Cancer	3.59 ^{**}	1.544–8.386	9.47 ^{**}	2.284–39.303
Neurological	1.31	0.599–2.871	4.94	0.983–24.839
Cardiovascular	0.63	0.280–1.424	0.18 [*]	0.042–0.729
Co-Morbidities	1.09	0.491–2.429	4.44	0.898–21.958
Year 2008	0.30 ^{**}	0.124–0.738	0.33	0.063–1.698
Year 2009	0.56	0.263–1.194	0.25	0.035–1.767
Year 2010	0.72	0.335–1.550	0.23	0.037–1.395

*
 $p < 0.05$,**
 $p < 0.01$,***
 $p < 0.001$

Note: OR, odds ratio; IRR, incidence rate ratio; CI, Confidence Intervals.