



Published in final edited form as:

Am J Hosp Palliat Care. 2017 March ; 34(2): 135–141. doi:10.1177/1049909115609589.

Pediatric primary care involvement in end-of-life care for children

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Abstract

Objectives—To examine the relationship between pediatric primary care involvement and hospice and home health care use at end of life.

Methods—California Medicaid data were used to estimate the relationship between pediatric primary care involvement and use of hospice and home health care using generalized estimating equations.

Results—Of the 2,037 children who died between 2007 and 2010, 11% used hospice and 23% home health. Among all children, primary care was not related to hospice use and was associated with home health use [usual source of care (OR=1.83, $p<0.05$), comprehensive care (OR=1.60, $p<0.05$), continuous care (low: OR=1.49, $p<0.05$; moderate: OR=2.57, $p<0.05$; high: OR=2.12, $p<0.05$)]. Primary care for children 15 to 20 years was related to hospice use [usual source of care (OR=4.06, $p<0.05$), continuous care (low: OR=4.92, $p<0.05$; moderate OR=4.09, $p<0.05$; high OR=3.92, $p<0.05$)]. Primary care for children under 5 years was associated with home health use [usual source of care (OR=2.59, $p<0.05$), comprehensive care (OR=2.49, $p<0.05$), continuous care (low: OR=2.22, $p<0.05$; moderate: OR=3.64, $p<0.05$; high: OR=3.62, $p<0.05$)]. For children 6 to 14 years, this association was seen with continuous care [moderate: (OR=2.38, $p<0.05$); high (OR=2.13, $p<0.05$)]. Home health for children 15 to 20 years was related to continuous care [moderate: (OR=2.32, $p<0.05$)].

Conclusions—Primary care involvement affected hospice use among older age groups and home health use among younger age groups. These findings underscore the need for clinical knowledge about end-of-life care for children of all ages among primary care providers.

INTRODUCTION

Of the 44,000 children who die in the United States each year,¹ most spend their last days in an acute care setting.² Although families increasingly desire their terminally-ill children receive end-of-life care at home,³ hospice and home health care are generally the only two

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Financial Disclosure: The authors have no financial relationships relevant to this article to disclose.

Conflict of Interest: The authors have no potential conflicts of interest to disclose

approaches to caring for children at end of life at home. As children's health conditions deteriorate and a prognosis of 6 months or less to live is given, children are eligible to receive hospice services. Hospice care focuses on comfort measures such as pain and symptom control with skilled nursing care, spiritual support, bereavement support, and medications/ supplies/ equipment related to terminal illness.^{4,5} The focus of home health care is different from hospice and involves restorative goals for the child and family. It includes skilled nursing care in the form of visits or nursing shifts, personal care assistance, speech, occupational and physical therapies, and equipment and medical supplies needed for home care.^{4,5} Comparisons between home health and hospice care suggest that hospice care provides better pain management,⁶ increased documentation of advanced directives,⁷ and lower infection rates.⁸

Recent reports and national guidelines have emphasized the critical role of pediatric primary care at end of life.^{4,9,10} Over 90% of US children have a pediatric primary care provider,¹¹ who can be an important source of information and referral for children and families to hospice or home health care. Several researchers of adult health care have begun exploring the role of primary care involvement in end-of-life care and have found that the end of life role is not well defined.¹²⁻¹⁵ We and others have previously reported that providing medical care for children and families at end of life can be challenging for primary care.¹⁶⁻²⁰ However, whether pediatric primary care involvement directly influences enrollment in end of life care remains incompletely understood.

In order to evaluate the effect of pediatric primary care involvement on receipt of hospice and home health care at the end of life, we used the Medicaid claims data of children who had died in California over a 4 year period. We further examined this relationship for different age groups of children.

METHODS

Data Sources

We conducted a retrospective analysis of the last calendar year of life using several data sources linked to Medicaid claims data. We used information from the 2007 to 2010 California Medicaid program's *Medicaid Analytic Extract* files, which are generated annually and administered by the Centers for Medicare and Medicaid Services (CMS).²¹ The data include demographic, enrollment, diagnosis, and service claims information for state Medicaid beneficiaries.²² The files also include specific information on primary care involvement and hospice and home health utilization. California conducts quality audits of Medicaid data prior to submission to CMS; however, CMS contracts with Mathematica Policy Research to review state data against tolerance criteria and assist states to make corrections, if need be. Reports have found no evidence of incomplete data or gross miscoding errors.²³ Data linked to the Medicaid files included the 2010 US Census files for California, which contain community demographic information, along with the California Department of Health Partners for Children Agency, which provided information on the counties under the California palliative care waiver (i.e., Nick Snow Children's Hospice and Palliative Care Act of 2006). US Census data quality is rigorously maintained by the US Census Bureau.²⁴ The Children's Hospital Association provided information on the location

of children's hospitals in California. We also used the California Office of Statewide Health Planning and Development's 2007 to 2010 *State Utilization Data File of Home Health Agencies and Hospice Facilities*, which contains information on California hospice agency demographics, to identify the location (i.e., latitude/longitude) of pediatric hospices. The data's quality was assessed through an initial automated review process and then a more rigorous review of potential errors and inconsistencies by California Office of Statewide Health Planning and Development.²⁵ All data were linked by zip code. The institutional review board of the University of Tennessee, Knoxville approved this study.

Study Sample

We included Medicaid beneficiaries who were 20 years or younger at death, died between January 1, 2007, and December 31, 2010, and were enrolled in the California Medicaid program for any part of their last calendar year of life. To ensure that beneficiaries died with a health-related condition, our sample was limited to children diagnosed with a complex chronic condition. We used the *International Classification of Diseases, 9th Revision*, (ICD-9-CM) codes in the Medicaid claims data to identify children with complex chronic conditions as defined by Feudtner et al.²⁶ Using the Medicaid beneficiaries' residence zip codes, we excluded children who resided outside of California. The final sample size was 2,037 pediatric decedents.

Measures

The Personal Summary records in the Medicaid files were used to identify children who utilized home health or received the Medicaid hospice benefit in their last calendar year of life. We confirmed that the children used hospice or home health care services through the Medicaid Other Services records, which includes detailed claims activity for home health and hospice enrollees. Using this information, we created two dichotomous variables indicating whether the child used hospice or home health care. Due to the small number, children enrolled in both home health and hospice care in the last calendar year of life were included in the hospice care category.

We used national guidelines, primary care literature, and the detailed primary care Medicaid claims information to create our measures of primary care involvement: usual source of care, comprehensive care, and continuous care.²⁷ Using the Medicaid Analytic Extract Other Services claim files and primary care CPT codes, we created the measures for primary care involvement. Usual source of care is where the child and family regularly receive primary care services.^{28,29} We operationalized this as whether the child was an established patient with the pediatric primary care provider.³⁰ Comprehensive care is defined as addressing the preventative, primary, and tertiary care needs of children,^{28,29} and was operationalized as whether the child received a comprehensive history and physical examination from pediatric primary care provider in the last calendar year of life.²⁷ Continuous care was repeated visits to the primary care provider,^{28,29} and we measured it as the number of primary care visits in the last calendar year of life and categorized them as none (0 visits), low (1 to 5 visits), moderate (6 to 10 visits), and high (11+ visits).^{31,32}

Covariates were chosen a priori based in the Andersen Behavioral Healthcare Utilization Model (i.e., predisposing, enabling, need) and previous literature examining hospice and home health use.^{33,34} Potential predisposing covariates included age, gender, race, and ethnicity.^{14,35–38} We categorized age at death as less than 1 year to 5 years, 6 to 14 years, or 15 to 20 years. Gender was a binary variable (0 = male, 1 = female). Race was categorized as Caucasian, other (African American, Asian, Pacific Islander), or unspecified. Ethnicity was dichotomized as whether or not the child was Hispanic.

Enabling covariates included hospice accessibility, inpatient medical accessibility, neighborhood socio-economic status, public policy support, and case management.^{39–43} Using the California Office of Statewide Health Planning and Development and Medicaid zip code data, hospice accessibility was defined as whether a child resided within 10 miles of a hospice provider that provided any pediatric care.⁴⁵ Using Children's Hospital Association data, inpatient medical accessibility was whether a children's hospital was present in the child's county of residence.⁴⁴ Using 2010 US Census data, we dichotomized neighborhood socio-economic status as whether a child's residence was in a neighborhood with an average household income above \$50,000/year.⁴⁵ Whether the child resided in a county covered by the California Palliative Care Waiver was a measure of public policy support developed from the Partners for Children Agency data.⁴⁵ Case management was defined as whether a child had an assigned Medicaid case manager.

Potential need covariates included diagnosis, comorbidity, disability status, psychological status, and functional status.^{14,15,32,34,35,46,47} We created separate variables for the diagnostic categories: cancer, congenital anomalies (e.g., chromosomal anomalies, genetic defects), cardiovascular conditions (e.g., heart and valve malformations, cardiomyopathies), and neurological conditions (e.g., moderate and severe intellectual disabilities, cerebral palsy, epilepsy) as described previously by Feudtner et al. Comorbidity was defined by whether the child had 2 or more complex chronic conditions.⁴⁴ We dichotomized disability status as whether the child was eligible for Medicaid coverage because of their disability status.⁴⁴ Psychological status was defined by whether the child received psychiatric care. Functional status was operationalized by the receipt of durable medical equipment, transportation services, personal care, or occupational therapy/physical therapy.

Analysis

The primary aim of the study was to examine the relationship between pediatric primary care involvement and hospice and home health care utilization among children in the last calendar year of life. Descriptive statistics were used to describe the children in the sample, including means, frequencies, minimums, maximums, and standard deviations. We conducted bivariate analyses of the study variables and found no evidence of multicollinearity. The Pearson chi-square test for differences in proportions and *t*-test for difference in means were used to provide comparisons between hospice and home health care use. Due to the binary nature of the dependent variables and longitudinal nature of the data, we used generalized estimating equations (GEE) to estimate the association between pediatric primary care involvement and hospice and home health utilization, while controlling for covariates. Separate regressions were conducted for each outcome. We

conducted a sensitivity analysis by age group to obtain a deeper understanding of the relationship between pediatric primary care involvement and hospice and home health care use. Results were reported as odds ratios (OR). Analyses were conducted using Stata 11.0 (StataCorp LP, College Station, TX) and ArcGIS Online (ESRI Inc., Redlands, California).

RESULTS

There were 2,037 children in the California Medicaid database who died with a complex chronic condition between 2007 and 2010. Of these children, 216 (10.6%) used hospice and 460 (22.6%) used home health care before they died (Table 1). Children receiving hospice care compared to those receiving home health care were more likely to have no continuous primary care involvement (31.0% vs. 20.8%) and more likely to have a cancer diagnosis (46.8% vs. 30.7%). Children receiving home health care more often had a usual source of primary care (78.9% vs. 67.6%), moderate continuous care (20.4% vs. 11.6%), access to inpatient medical care (70.0% vs. 59.3%), and a case manager (42.0% vs. 24.1%) than children receiving hospice care. The home health care children were also more likely to have cardiovascular conditions (39.4% vs. 23.2%), and reduced psychological (39.6% vs. 31.5%) and functional (92.4% vs. 80.1%) status compared to children receiving hospice care.

For all children in the sample, we found no evidence that primary care involvement was related to use of hospice care (Table 2); however, pediatric primary care involvement was associated with home health care use (Table 3), after controlling for predisposing, enabling, and need characteristics of the children and families. Usual source of care (OR=1.83, $p<0.05$), comprehensive care (OR=1.60, $p<0.05$), low continuous care (OR=1.49, $p<0.05$), moderate continuous care (OR=2.57, $p<0.05$), and high continuous care (OR=2.12, $p<0.05$) were significantly associated with home health care use.

In sub-group analyses (Table 2), we found that the odds of using hospice were 4 times higher for children 15 to 20 years with a usual source of care (OR=4.06, $p<0.05$) and those with low (OR=4.92, $p<0.05$), moderate (OR=4.09, $p<0.05$), and high (OR=3.92, $p<0.05$) continuous care. Pediatric primary care involvement was not significantly related to hospice use in other age categories.

With regards to home health care, we found that primary care involvement was associated with greater use of home health care in multiple age categories (Table 3). In the < 1 year to 5 year group, greater home health care use was associated with usual source of care (OR=2.59, $p<0.05$), comprehensive care (OR=2.49, $p<0.05$), and continuous care (low: OR=2.22, $p<0.05$; moderate: OR=3.64, $p<0.05$; high: OR=3.62, $p<0.05$). In the 6 to 14 year group, this association was seen only with continuous care: moderate (OR=2.38, $p<0.05$) and high (OR=2.13, $p<0.05$). Children 15 to 20 years had increased odds of using home health when they had moderate continuous care (OR=2.32, $p<0.05$).

DISCUSSION

As one of the first studies to examine hospice and home health care use for children, this study sought to understand the impact of pediatric primary care involvement on the use of hospice and home health by children and their families. We found that pediatric primary care

involvement was associated with increased hospice use for older children, and increased home health use for younger children.

We found primary care involvement to be associated with hospice use only in the 15 to 20 year age group. Previous work supports the idea that older children with a usual source of continuous primary care and their families may have established a long-term relationship with their primary care provider compared to younger children.⁴⁸ Continuous primary care may assist older children and their families in making treatment decisions and plans for end of life.^{31,49} In addition, older children may be better able to articulate their wishes and plan for their end-of-life care.⁵⁰ For example, tools such as Voicing My Choices™ are specifically designed to engage older children in the discussion of end-of-life care.⁵¹ The primary care setting may be a comfortable setting for older children to engage in a conversation and express their wishes about end-of-life care, particularly hospice care. Thus, further investigation into what occurs during a pediatric primary care examination may shed additional insight into the nature of the involvement with older children.

Recent evidence suggests that providers with a child-only scope of practice (e.g., pediatrician) may be less likely to engage in conversations about changing health needs compared to providers with a life-span scope of practice (e.g., family medicine physician).⁵² It may be the family medicine physicians with a large scope of practice may be more comfortable discussing and writing orders for hospice for older children because of their experience with adult patients. Additionally, pediatricians often have very limited experience conducting conversations about end of life and lack knowledge about end-of-life care resources in their community.^{19,20} Therefore, research should continue investigating the effect of provider scope of practice on the use of end-of-life care among children.

The findings that children under 15 years with a usual source of comprehensive and continuous primary care were more likely to use home health care was interesting. Although our data did not allow us to examine the type of primary care providers, it is possible that the scope of practice among primary care providers may have influenced patients' use of home health care among younger children. For children with serious illnesses, especially those who are young, there is often a need for home health nursing services in addition to hospice services. Parents may have chosen not to elect hospice services for fear of losing needed home health services. These needs may not be as high for older children and hence a higher use of hospice services in the 15 –20 year age group.

The Patient Protection and Affordable Care Act of 2010 has a new provision, Concurrent Care for Children [Section 2302], that requires states to provide hospice services to children younger than 21 years along with cure-oriented treatment. Since our study used a sample of 2007 to 2010 Medicaid beneficiaries, our findings must be interpreted in the context of the policy environment prior to the implementation of the Concurrent Care provision of the Affordable Care Act. Prior to the ACA Section 230, families had to choose between cure-oriented treatments versus hospice services for their children with resultant decreased hospice utilization especially for younger children. Given that the Medicaid and Children's Health Insurance Program (CHIP) rules for joint use of hospice and home health care were modified in some states (i.e., states with combination Medicaid and CHIP program), our

findings are still relevant for families making choice with their providers about end of life service utilizations. Future studies should examine the effect of the Concurrent Care provision in reducing barriers to access to hospice care for children.

There are several limitations of this study to mention. Although we operationalized primary care involvement as done previously, our measure may not have captured all aspects of usual source of care, comprehensive and continuous care. These findings underscore the need for clinical knowledge about end of life care for children. There was also the potential selection bias in the Medicaid data set, which includes only children enrolled in fee-for-service Medicaid and Children's Health Insurance Plan (CHIP). These findings may not be generalized to managed care Medicaid beneficiaries or those outside of California. Another limitation was that our data set included the last calendar year of life for the children enrolled in Medicaid. Thus, our database did not include a comprehensive claims history for children in the study. There may be other confounding factors that are related to hospice and home health use that were not reflected in our model such as the role of specialist physicians such as oncologists, and whether the children received a palliative care consultation. Additionally, we do not know whether the hospice and home health referrals were made by primary-care, specialist or palliative care physician. Our study found significant effect of primary care involvement on hospice use in older children and on home health care in the younger age group at the end of life.

Acknowledgments

Funding Source: This publication was made possible by Grant Number K01NR014490 from the National Institute of Nursing Research. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Institute of Nursing Research or National Institutes of Health.

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Table 1

Descriptive Statistics of Study Variables by Hospice and Home Health Care Use

Variables	Total	Hospice Use	Home Health Use	P value
	(N=2,037) N (%)	(n=216) n (%)	(n=460) n (%)	
Primary Care Involvement				
Usual Source of Care	1,285 (63.1%)	146 (67.6%)	363 (78.9%)	0.002
Comprehensive Care	673 (33.0%)	88 (40.7%)	223 (48.5%)	0.058
Continuous Care				
None	733 (36.0%)	67 (31.0%)	96 (20.8%)	0.004
Low	692 (34.0%)	76 (35.2%)	157 (34.1%)	0.779
Moderate	272 (13.4%)	25 (11.6%)	94 (20.4%)	0.005
High	340 (16.7%)	48 (22.2%)	113 (24.6%)	0.495
Age				
< 1 year to 5 years	853 (42.4%)	94 (43.5%)	208 (45.2%)	0.679
6 to 14 year	588 (28.9%)	64 (29.6%)	151 (32.8%)	0.405
15 to 20 years	586 (28.8%)	58 (26.9%)	101 (22.0%)	0.162
Female	961 (47.2%)	105 (48.6%)	242 (52.6%)	0.332
Race				
Caucasian	351 (17.2%)	41 (19.0%)	94 (20.4%)	0.671
Other	268 (13.2%)	***	47 (10.2%)	0.904
Unspecified	1,418 (69.6%)	154 (71.3%)	319 (69.4%)	0.615
Hispanic	751 (36.9%)	73 (33.8%)	151 (32.8%)	0.797
Hospice Accessibility	1,639 (80.5%)	176 (81.5%)	370 (80.4%)	0.735
Inpatient Medical	1,291 (63.4%)	128 (59.3%)	322 (70.0%)	0.006
Neighborhood socio-economic Status	0.40 (0.15)	0.41 (0.15)	0.43 (0.15)	0.623
Public Policy Support	***	31 (14.4%)	***	0.833
Case Management	595 (29.2%)	52 (24.1%)	193 (42.0%)	0.001
Diagnosis				
Cancer	589 (28.9%)	101 (46.8%)	141 (30.7%)	0.001
Congenital Anomalies	374 (18.4%)	41 (19.0%)	105 (22.8%)	0.263
Cardiovascular Conditions	821 (40.3%)	50 (23.2%)	181 (39.4%)	0.001
Neurological Conditions	1,083 (53.2%)	123 (56.9%)	289 (62.8%)	0.143
Comorbidities	989 (48.6%)	116 (53.7%)	264 (57.4%)	0.366
Disability Status	1,843 (90.5%)	195 (90.3%)	431 (93.7%)	0.115
Psychological Status	569 (27.9%)	68 (31.5%)	182 (39.6%)	0.042
Functional Status	1,608 (78.4%)	173 (80.1%)	425 (92.4%)	0.001

Note:

*** Unable to report less than 10% per Medicaid Data Use Agreement

Table 2
 Association Between Pediatric Primary Care Involvement and Hospice Use, Stratified by Age Groups[#]

Variables	All Children N = 2,037		<1 to 5 Years n = 863		6 to 14 Years n = 588		15 to 20 Years n = 586	
	Adjusted OR	(SE)	Adjusted OR	(SE)	Adjusted OR	(SE)	Adjusted OR	(SE)
Usual Source of Care	1.21	(0.22)	0.89	(0.25)	0.87	(0.32)	4.06	(1.82)**
Comprehensive Care	1.32	(0.24)	1.43	(0.43)	1.24	(0.41)	1.25	(0.45)
Continuous Care								
None	(ref)		(ref)		(ref)		(ref)	
Low	1.30	(0.26)	1.02	(0.30)	0.92	(0.37)	4.92	(2.40)***
Moderate	0.99	(0.27)	0.87	(0.38)	0.43	(0.25)	4.09	(2.37)*
High	1.45	(0.37)	0.92	(0.40)	1.15	(0.53)	3.92	(2.25)*

* $p < 0.05$,

** $p < 0.01$,

*** $p < 0.001$

Note: OR, Odds Ratio; SE, Standard error

[#] Adjusted for gender, race, ethnicity, hospice accessibility, inpatient medical accessibility, neighborhood socio-economic status, public policy support, case management, cancer, congenital anomalies, cardiovascular conditions, neurological conditions, comorbidity, disability status, psychological status, and functional status

Table 3

Association Between Pediatric Primary Care Involvement and Home Health Use, Stratified by Age Groups[#]

Variables	All Children N = 2,037		<1 to 5 Years n = 863		6 to 14 Years n = 588		15 to 20 Years n = 586	
	Adjusted OR	(SE)	Adjusted OR	(SE)	Adjusted OR	(SE)	Adjusted OR	(SE)
Usual Source of Care	1.83	(0.27)***	2.59	(0.62)***	1.62	(0.41)	1.64	(0.50)
Comprehensive Care	1.60	(0.21)***	2.49	(0.51)***	1.09	(0.22)	1.40	(0.39)
Continuous Care								
None	(ref)		(ref)		(ref)		(ref)	
Low	1.49	(0.23)**	2.22	(0.56)***	1.21	(0.34)	1.26	(0.42)
Moderate	2.57	(0.49)***	3.64	(1.14)***	2.38	(0.82)*	2.32	(0.91)*
High	2.12	(0.43)***	3.62	(1.19)***	2.13	(0.75)*	1.42	(0.58)

* $P < 0.05$,** $P < 0.01$,*** $P < 0.001$

Note: OR, Odds Ratio; SE, Standard error

[#] Adjusted for gender, race, ethnicity, hospice accessibility, inpatient medical accessibility, neighborhood socio-economic status, public policy support, case management, cancer, congenital anomalies, cardiovascular conditions, neurological conditions, comorbidity, disability status, psychological status, and functional status