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The effect of pediatric palliative care policy on hospice utilization among California Medicaid beneficiaries

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Abstract

Background—California implemented pediatric palliative care legislations that allowed children to receive curative and supportive care from diagnosis of a life-threatening, serious illness in 2010. Palliative care policies may improve access to hospice care as children near end of life.

Objectives—To examine the effect of the palliative care policy on hospice utilization for children and their families was investigated.

Research Design—Using 2007 and 2010 California Medicaid data, a difference-in-difference analysis was conducted to analyze hospice use (i.e., hospice enrollment, hospice length of stay) changes for children who resided in pediatric policy counties relative to those who did not.

Population Studied—The sample of children in California who died with a life-threatening, serious illness in 2007 and 2010 equaled 979 children.

Results—Over 10% of children enrolled in hospice care with an average of less than 3 days of hospice care. The palliative care policy did not have any effect on hospice enrollment. However, the policy was positively associated with increasing days in hospice care (IRR= 5.61, $p<0.05$). The rate of hospice length of stay increased by a factor of 5.61 for children in palliative care counties, compared to children unaffected by the policy.

Conclusions—The pediatric palliative care policy was associated with longer lengths of stay in hospice once the children were enrolled. Policies promoting palliative care are critical to ensuring access to hospice care for children.

Keywords

Pediatric Hospice Utilization; Pediatric Palliative Care Policy; Medicaid; Andersen Behavioral Model

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INTRODUCTION

There are approximately 42,000 pediatric deaths each year in the United States (1). Many of these children die with life-limiting health conditions yet are never enrolled in hospice care. In fact, less than 10% of children with life-limiting conditions utilize hospice at end of life (2). Pediatric hospice care is defined as medical and supportive care services for children and their families that is delivered by a multidisciplinary team of clinicians in the home, hospital, or dedicated facility (3). The physical and psychosocial benefits of pediatric hospice care are documented (4), and recommended by the Institute of Medicine (3,5), American Academy of Pediatricians (6), and the National Association of Neonatal Nurses (7).

Although family, clinician, and organizational factors influence pediatric hospice care utilization (8-10), the hospice care benefit itself may influence use (11,12). Hospice eligibility for Medicaid beneficiaries requires that children have a life expectancy of approximately six months or less as certified by a hospice medical director and an attending physician or nurse practitioner. The Concurrent Care for Children provision (section 2302) of the Patient Protection and Affordable Care Act of 2010 eliminated the Medicaid hospice eligibility requirement that children discontinue all life-prolonging or curative care (i.e., chemotherapy, dialysis, bone marrow transplant, antiretroviral regimens, radiation, and transplant rejection medication) upon hospice enrollment (13,14). The remaining hospice eligibility requirement of six months or less to live, however, is counter to optimal end-of-life care for children because it does not take into account the medical needs or preference of children and their families throughout the course of a serious illness trajectory. Often families are forced to make very difficult choices between treating a child's disease or managing quality of end of life (15-17). Consequently, many families continue treatments and therapies and delay hospice care enrollment (18,19).

Several states have initiated legislation to address this barrier. In 2005, the United States Department of Health and Human Services assisted states in waiving hospice eligibility by supporting pediatric palliative care policies. Florida, Massachusetts, Washington, Colorado, Illinois, and California responded with state-level policies referred to as pediatric palliative care policies (20). Most palliative care policies enabled children with life-limiting conditions to access supportive services at diagnosis that were concurrent with their treatments and therapies. Financing was generally through a Medicaid waiver that allowed the states to pay for these services.

In California, a state with the highest pediatric Medicaid population (21), the Children’s Hospice and Palliative Care Coalitions, pediatric hospices, state legislators, and state health officials worked through a three-year pediatric palliative care demonstration project to gain the legislative support for a state law and Medicaid waiver for pediatric palliative care (20,22). Under the Nick Snow Children’s Hospice and Palliative Care Act of 2006 (Assembly Bill 1745), the California State Department of Health Care Services developed a pediatric palliative care program for Medicaid beneficiaries that was implemented in January, 2010 (12,13). The program provides in-home palliative care regardless of a child’s life expectancy and does not require a prognosis of 6 month or less to live (23,24). Services include pain and symptom management, access to a 24/7 nurse line, family education, respite care, expressive therapies, and family counseling (24). To participate in the program, children and families must reside in one of the 11 participating counties, be 20 years of age or younger, and have an eligible medical condition (23,24). Thus, California became one of the few states to enact pediatric palliative care legislation for children with life-limiting conditions and their families.

Given that most studies of state pediatric palliative care policies have described the programs implemented (12,25-26), none have explored their influence on hospice care. Recent adult studies have shown that patients receiving palliative care often have enhanced hospice enrollment and longer lengths of stay in hospice (27-31). Children receiving palliative care may transition to hospice care as end of life nears, where they would receive intensive pain and symptom management along with bereavement services. Care can also transition from the home to a hospice facility, if needed. Palliative care policies may improve access to hospice care as children near end of life. Therefore, the purpose of this study was to examine the effect of the pediatric palliative care policy on hospice utilization.

METHODS

This study used a natural experiment design to examine the effect of pediatric palliative policy on hospice utilization, while controlling for child and family characteristics. To be included in the study, participants had to be between the ages of 0 and 20 years, died between January 1, 2007 and December 31, 2007 and January 1, 2010 and December 31, 2010, enrolled in the California Medicaid program for any part of their last calendar year of life, and had a diagnosis of a life-limiting, serious illness as classified by Feudtner and colleagues (32). The year 2007 was selected for analysis because it represented a year prior to the approval of the pilot program in 2008 and was unaffected by policy change. Non-California residents, Medicaid managed care plan beneficiaries, and participants with missing entries were excluded. The sample consisted of 979 children after applying these inclusion and exclusion criteria. The Institutional Review Board at the University of Tennessee, Knoxville approved this study.

Data from the *Medicaid Analytic Extract* (MAX) claims files, which are administered by the Centers for Medicare and Medicaid Services (CMS) were used (33). For this study, the MAX Person Summary and Other Services files were used. These files contain information collected from Medicaid billing records including demographics, International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9) procedures, diagnoses, payment, and dates of service. Data from 2007 and 2010 Medicaid claims data from California was used because these years occurred prior to policy change and after implementation of the policy. California was chosen because it had the largest population of children enrolled in Medicaid (21), was one of a few states to implement pediatric palliative care legislation, and had a relatively large sample size.

Other data sources for this study included the California Office of Statewide Health Planning and Development State Utilization (CA OSHPD) Data File of Home Health Agency and Hospice Facilities from fiscal year 2007 to fiscal year 2010 that contain addresses of pediatric hospice providers. The California Department of Health Partners for Children Agency, provided information on the counties participating in the pediatric palliative care policy. Data sources were merged manually by Federal Information Processing Standards (FIPS) code.

Two measures of hospice utilization were created: hospice enrollment and hospice length of stay. The first measure of *hospice enrollment* was defined as whether or not a child was enrolled in hospice care during the last calendar year of life (34,35). This variable was created using data from the MAX Personal Summary Record type of service indicator code 35 for hospice and confirmed in the MAX Other Services Record using revenue codes 651, 652, 655, and 656. The second measure was *hospice length of stay*, which was the number of days a child was enrolled in hospice care. Daily counts of hospice care service were derived from the per diem payments to hospice using the MAX Other Services hospice revenue codes.

To examine the influence of the pediatric palliative care policy, an interaction term was created. *Palliative county,* which was a binary indicator of whether or not a child and their family resided in a pediatric palliative care policy county and *post policy,* which was a binary measure for observations in 2010 were interacted. The interaction represented the change over time in hospice utilization for children who resided in a palliative county, compared to those who did not. A positive relationship of the interaction to the outcome indicated that hospice enrollment or length of stay for children in palliative counties increased post policy implementation, compared to children in non-palliative counties.

A group of children and family covariates were created a-prior based on the Andersen Behavioral Model of Health Services Use: predisposing (i.e., age, gender, race/ethnicity), enabling (i.e., private insurance, usual source of care, hospice service area) and need (i.e., diagnosis, comorbidities, health status) characteristics (36). Age was categorized as less than 1 year to 5 years of age, 6 to 14 years, or 15 to 20 years. Gender was male or female. A child's race was classified as Caucasian or non-Caucasian and ethnicity was Hispanic or non-Hispanic. Whether or not a child had private health insurance in addition to Medicaid was a measure of private insurance. Usual source of care was whether or not a child was an established patient with a primary care provider. A measure of hospice service area was created that categorized children whether or not they resided within 10 miles of a pediatric hospice provider, using mapping software. Individual measures were created for the diagnosis to measure the presence and absence of a cancer, congenital, neurological, and cardiovascular conditions. Comorbidities were defined as having two or more complex chronic conditions. Whether or not a child was eligible for Medicaid coverage because of his/her disability status was the measure of disability status. Psychological status was operationalized as whether or not a child received any psychiatric care. Functional status was defined as whether or not a child used durable medical equipment, transportation service, personal care, or occupational/physical therapy.

A difference-in-difference approach was used for statistical analysis. This approach is commonly used to evaluate the effect of policy changes (37), and compares pre- and post-policy changes in outcomes between a treatment group (exposed to policy change) and a comparison control group (not exposed to policy change). Children who resided in counties that did participate in the pediatric palliative care policy as the treatment group and children who did not reside in pediatric palliative care policy counties as the control group were chosen. The study included 2007 as a pre-policy year and 2010 as the post-policy year. Separate analyses were conducted for hospice enrollment and hospice length of stay, using logistic and negative binomial regressions, respectively (38). Descriptive statistics for study variables were calculated to examine the data and confirm statistical assumptions. For the study, all analyses were performed using Stata 11.0 (StataCorp LP, College Station, TX) and ArcGIS Online (ESRI Inc., Redlands, California).

RESULTS

The summary statistics for the variables in the analysis are presented in Table 1 and Table 2. In the overall sample, more than 10% of children enrolled in hospice care with an average of less than 3 days of hospice care. Over half (54.4%) of the children and their families lived in counties that participated in the pediatric palliative care policy. The most common age group were children less than a year to 5 years of age (41.7%). Boys and girls were evenly represented in the sample. Less than 20% of children were Caucasian and less than 40% of children were Hispanic. Although only 12.5% of children had additional private insurance, most children had a usual source of care (60.9%) and access to pediatric hospice care (81.0%). Neuromuscular conditions were the most common in the sample at 53.1% with almost half of the children experiencing multiple conditions (44.5%). Children were often disabled (90.3%) with limited functional status (79.8%) and a quarter had reduced psychological health status.

The difference-in-difference estimates of the palliative care policy effect are shown in Table 3. The policy effect on hospice enrollment and hospice length of stay are reported as separate results. The regression analysis showed that the palliative care policy (i.e., interaction between palliative policy county and year 2010) did not have any effect on hospice enrollment. However, the palliative care policy was positively and significantly associated with increasing days in hospice care (IRR= 5.61, $p<0.05$). The rate of hospice length of stay increased by a factor of 5.61 for children in palliative care counties, compared to children unaffected by the policy.

The results also revealed that several covariates were related to hospice utilization (Table 3). Children 6 to 14 years (OR = 0.54, $p<0.05$) with private insurance (OR=0.38, $p<0.05$) and a cardiovascular diagnosis (OR=0.36, $p<0.01$) had reduced odds of enrolling in hospice care, while children with a cancer (OR=3.68, $p<0.001$) or neuromuscular (OR=1.75, $p<0.05$) diagnosis were positively related to hospice enrollment. Other characteristics related to decreased hospice length of stay included 6 to 14 years of age (IRR=0.13, $p<0.01$), 15 to 20 years of age (IRR=0.26, $p<0.05$), residing in the hospice service area (IRR=0.26, $p<0.05$), and a cardiovascular diagnosis (IRR=0.08, $p<0.001$). Child and family covariates associated with increased hospice stay were a cancer (IRR=16.59, $p<0.01$) or neuromuscular (IRR=12.31, $p<0.001$) diagnosis.

DISCUSSION

As one of the first studies to examine the implementation of pediatric palliative care policy, the goal of this study was to understand the influence of the policy on hospice utilization: enrollment and length of stay. Based on the descriptive analysis, hospice enrollment and length of stay increased from 2007 to 2010, but this was not statistically significant. These findings were consistent with other studies indicating that a small percentage of children used hospice care at end of life and often for just a few days (39,40). This evidence suggests that during the study timeframe children generally had relatively low rates of hospice utilization.

This study demonstrated that children who resided in pediatric palliative care policy counties were no less likely to enroll in hospice care relative to their counterparts who did not have access to the palliative care policy. The hospice enrollment finding was consistent with Wang and colleagues (31), who found in a study of adult Medicaid patients with cancer, that palliative care had no significant effect on hospice enrollment. The findings from this study are, however, inconsistent with several studies that showed palliative care positively influences adult hospice enrollment (27-29). It is possible that children and families in this study may have remained in palliative care until the death of the child. The services offered by the pediatric palliative care policy may have met the needs of families. Additionally, families may have continued to seek curative care for their children even up to the end of their disease trajectory, rather than enroll in hospice care (41,42). Although the study data did not allow for an investigation of family decision-making, future research might examine the family and child attitudes towards palliative care as a means of transitioning to hospice care at end of life.

It was interesting that for those children who did enroll in hospice care in policy-affected counties, they had longer lengths of stay in hospice. This finding was consistent with previous studies (28,30,31). The finding suggests that palliative care policies may be successful at promoting the continuum of care at end of life for children. Palliative care policies may also ensure that families receive the optimal care from hospice that is often linked to days enrolled in hospice care (43). Hospice care for a patient admitted and actively dying requires significant time and resources from hospice staff to conduct the initial assessment, consult with the hospice team, and provide hospice services while the child is dying. Additional days of hospice enrollment mean that the hospice staff can provide effective pain and symptom management, social work services, or pastoral care. Further research is needed to examine the influence of pediatric palliative care policies on quality of end-of-life care for children and their families.

Findings from this study need to be interpreted in light of several limitations. The study did not capture the long term effects of the pediatric palliative care policy change. The effect of policy change on the utilization of hospice care may take a longer time to emerge and children, families, and providers become more familiar with the palliative care policy. In addition, this nonexperimental study may not have captured unobserved factors that might be related to hospice utilization. The difference-in-difference approach was used to minimize the influence of time-invariant unobserved factors, but not those time-varying unobserved factors such as changes in child or family circumstances that might influence hospice utilization. Furthermore, family and provider views, along with cultural norms about hospice utilization, may have shifted since the timeframe of this study. With the advent of Concurrent Care for Children in the 2010 Affordable Care Act, health care policy may continue to influence utilization. Finally, the data in our analysis was truncated. Truncated data is incomplete data because a systematic selection process. For this study the systematic selection process was that only children in the that last year of life were included. Thus, a child might have hospice claims in the prior year. We evaluated the extent that our data were truncated and potentially biased. We found less than 0.5% of the children may have had claims in the prior year. Consequently, modeling truncation was not included in the analysis plan.

The goal of this analysis was to examine whether the California pediatric palliative care policy was associated with improved hospice utilization after taking into account child and family characteristics. This study provides one of the first estimates of the impact of pediatric palliative care policy on hospice utilization among children. The pediatric palliative care policy had no effect on hospice enrollment; however, it was associated with longer lengths of stay in hospice once the children were enrolled. Policies promoting palliative care are critical to ensuring access to hospice care for children.

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Table 1

Descriptive Statistics of Study Variables (N=979)

	Total **N=979** **n (% or Mean)**
Hospice Enrollment	113 (11.54%)
Hospice Length of Stay	979 (2.65)
Palliative County	533 (54.44%)
Age	
< 1 year to 5 years	408 (41.68%)
6 to14 years	290 (29.62%)
15 to 20 years	281 (28.70%0
Female	457 (46.68%)
Race	
Caucasian	185 (18.90%)
Non-Caucasian	794 (81.10%)
Hispanic	378 (38.61%)
Private Insurance	122 (12.46%)
Usual Source of Care	596 (60.88%)
Hospice Service Area	793 (81.00%)
Cancer	286 (29.21%)
Congenital	164 (16.75%)
Neuromuscular	520 (53.12%)
Cardiovascular	365 (37.28%)
Comorbidities	436 (44.54%)
Disability Status	884 (90.30%)
Psychological Status	251 (25.64%)
Functional Status	781 (79.78%)

Table 2

Descriptive Statistics by Pre- and Post-Policy and Palliative and Non-Palliative County (N=979)

	Pre-Policy 2007 (n=498)		**Post Policy 2010 (n=481)**	
	PC (n=267) % or mean/SD	**Non-PC (n=231) % or mean/SD**	**PC (n=266) % or mean/SD**	**Non-PC (n=215) % or mean/SD**
Hospice Enrollment	10.00%	11.26%	12.78%	12.56%
Hospice Length of Stay	1.54(7.69)	2.82(14.27)	3.57(18.98)	2.71(15.28)
Age				
< 1 year to 5 years	39.70%	43.29%	44.74%	38.60%
6 to14 years	31.09%	29.00%	29.70%	28.37%
15 to 20 years	29.21%	27.71%	25.56%	33.02%
Female	50.94%	46.32%	43.61%	45.58%
Caucasian	15.73%	24.24%	13.53%	23.72%
Hispanic	39.33%	34.63%	42.48%	37.21%
Private Insurance	12.36%	11.69%	14.29%	11.16%
Usual Source of Care	64.04%	60.61%	57.89%	60.93%
Hospice Service Area	86.89%	72.29%	90.98%	70.70%
Cancer	35.96%	23.81%	28.57%	27.44%
Congenital	19.10%	15.58%	15.78%	16.28%
Neuromuscular	49.44%	50.65%	55.26%	57.67%
Cardiovascular	33.71%	44.59%	36.47%	34.88%
Comorbidities	48.31%	41.56%	44.74%	42.79%
Disability Status	90.64%	87.01%	91.73%	91.63%
Psychological Status	33.33%	25.54%	24.44%	17.67%
Functional Status	77.90%	80.09%	76.32%	86.05%

Note: PC = palliative county

Table 3

Difference-in-Difference Estimation Analysis (N=979)

	Hospice Enrollment		**Hospice Length of Stay**	
	OR	**(95% CI)**	**IRR**	**(95% CI)**
Policy Effect				
Palliative County × Post Policy	1.67	(0.73-3.83)	5.61	(1.14-27.70) *
Palliative County	0.66	(0.35-1.22)	0.29	(0.08-1.12)
Post Policy	0.94	(0.51-1.72)	0.64	(0.17-2.42)
Covariates				
6 to14 years	0.54	(0.31-0.92) *	0.13	(0.40-0.43) **
15 to 20 years	0.86	(0.51-1.45)	0.26	(0.07-0.97) *
Female	1.23	(0.81-1.87)	1.31	(0.55-3.16)
Caucasian	0.98	(0.55-1.77)	1.28	(0.37-4.46)
Hispanic	0.90	(0.56-1.44)	1.68	(0.66-4.29)
Private Insurance	0.38	(0.17-0.88) *	0.51	(0.11-2.31)
Usual Source of Care	1.16	(0.71-1.91)	1.22	(0.44-3.36)
Hospice Service Area	0.84	(0.49-1.44)	0.26	(0.08-0.81) *
Cancer	3.68	(2.09-6.46) ***	16.59	(3.24-84.99) **
Congenital	1.55	(0.84-2.86)	12.31	(3.19-47.47) ***
Neuromuscular	1.75	(1.03-2.98) *	3.28	(0.89-12.06)
Cardiovascular	0.36	(0.20-0.66) **	0.08	(0.02-0.30) ***
Comorbidities	1.02	(0.56-1.85)	1.53	(0.46-5.07)
Disability Status	0.88	(0.45-1.70)	0.38	(0.10-1.48)
Psychological Status	0.78	(0.46-1.31)	0.45	(0.15-1.31)
Functional Status	0.72	(0.41-1.27)	1.40	(0.45-4.31)

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

$^{*}p < 0.05$,

$^{**}p < 0.01$,

$^{***}p < 0.001$