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Multiple Complex Chronic Conditions and Pediatric Hospice Utilization among California Medicaid Beneficiaries, 2007–2010

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Abstract

Background: Over 42,000 children die each year in the United States, including many with multiple complex chronic conditions (MCCCs), but little is known about whether the presence of MCCCs influences families to utilize pediatric hospice care.

Objective: The study objective was to examine the relationship between MCCCs and pediatric hospice utilization among Medicaid beneficiaries.

Methods: A retrospective, longitudinal cohort design was conducted with 2007–2010 California Medicaid data to examine the relationship between MCCCs (i.e., two or more MCCCs) and pediatric hospice utilization (i.e., hospice enrollment, hospice length of stay). Multivariate logistic regression with year fixed effects examined the effect of MCCCs on hospice enrollment, and negative binomial model with year fixed effects explored the relationship between MCCCs and hospice length of stay.

Results: More than 10% of children enrolled in hospice care with an average length of stay of approximately three days. In the study sample, 48.6% of the children had MCCCs. MCCCs were not significantly related to hospice enrollment. However, children with MCCCs (incidence rate ratios = 4.25, $p < 0.01$) were associated with an increase in the number of days in hospice care.

Conclusions: This study demonstrated that children with MCCCs have limited hospice care utilization at end of life. Future research is needed to explore barriers to hospice care for children with MCCCs.

Keywords: children; complex chronic conditions; end of life; hospice; Medicaid

Introduction

Over 42,000 children die each year in the United States, including many with multiple complex chronic conditions (MCCCs).[1,2] By definition, children with MCCCs have several life-limiting health conditions that affect two or more body systems.[3,4] These children generally have increased hospital admissions and emergency room visits, especially in the last year of life.[5–8] The costs of care for children with MCCCs can range from $147,000 to $687,000 in their final year.[5]

As the health of children with MCCCs deteriorates and families are given a prognosis of six months or less to live for their child, pediatric hospice care is a service available for children and their families. For children who have a life-limiting illness, pediatric hospice is a vital home-based service offered by a multidisciplinary team of clinicians that reduces symptoms and suffering for children and their families during end-stage MCCC illness.[9] Hospice is often used interchangeably with palliative care, but clear distinctions exist. Pediatric palliative care is medical care for children at any age or stage of a life-limiting condition with the goal of improving quality of life during MCCCs.[10] Both hospice care and palliative care are family-centered approaches to comfort and support.

Although families of children with MCCCs increasingly desire for their children to be pain and symptom free at end of life in the comfort of their home,[11,12] little is known about whether the presence of MCCCs influences families to utilize pediatric hospice services. From the literature on MCCCs at end of life, the findings are sparse and inconsistent. Adult researchers have reported no relationship between MCCCs and hospice utilization,[13,14] while others have found a significant decline in the proportion of patients with multiple

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conditions using hospice care.[15] Initial work examining pediatric MCCCs at end of life has been primarily descriptive and methodological.[16,17] No studies were identified that explored the relationship between MCCCs and pediatric hospice utilization. As children experience additional complex chronic conditions with multiple systems failing at end of life, one might hypothesize that their families are more likely to enroll their children in hospice for longer lengths of stay to ensure that pain and symptoms are managed at end of life.

Improving our knowledge of pediatric hospice utilization among this underserved and understudied population is important. Given the current environment of concurrent care for children (Affordable Care Act provision 2302), which enables Medicaid children and their families to seek hospice care while concurrently receiving treatment for their health conditions, MCCCs may be a significant predictor of hospice utilization. Understanding whether MCCCs affect hospice enrollment and length of stay may ultimately impact the quality of end of life for these children and their families. Therefore, the purpose of this study was to examine the relationship between MCCCs and pediatric hospice utilization among children at end of life.

Methods

Design and sample

A retrospective, longitudinal cohort design was conducted with Center of Medicare and Medicaid Services Medicaid data to examine the relationship between MCCCs and pediatric hospice utilization. Children were included in the study if they died between January 1, 2007, 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 complex chronic condition (i.e., neuromuscular, cardiovascular, respiratory, renal, gastrointestinal, hematologic, metabolic, congenital, cancer). Diagnoses were based on the *International Classification of Diseases, 9th revision,* (*ICD-9*) codes as recommended by Feudtner et al.[3,4] Children were excluded from the study if they participated in Medicaid-managed care plans, had missing entries, or were non-California residents. After applying the inclusion and exclusion criteria, the final sample was 2036 children. The Institutional Review Board of the University of Tennessee, Knoxville, approved this study.

Data sources

The main data source was the 2007–2010 California Medicaid claims files (Medicaid analytic extract [MAX]). The MAX Person Summary files provided demographic, health status information and healthcare services, and the MAX Other Services files provided *ICD-9* diagnosis codes and current procedural terminology (CPT) codes for healthcare services. The California Office of Statewide Health Planning and Development State Utilization Data File of Home Health Agency and Hospice Facilities from fiscal years 2007–2010 were also used because they contained the addresses of pediatric hospice providers. This information was used to construct a geographic measure of pediatric hospice provider accessibility. Data on the counties that provided public policy support for pediatric end-of-life care (i.e., Nick Snow Children's Hospice and Palliative Care Act of 2006) were obtained from the California Department of Healthcare Services, Partners for Children department. To create a comprehensive data set for this study, all data were manually merged by federal information processing standards code.

Measures

Dependent variables. Two measures of hospice utilization were developed for this study: *hospice enrollment* and *hospice length of stay.*[16,18] Hospice enrollment was defined as whether or not children enrolled in hospice care during the last calendar year of life. Data were obtained from the MAX Person Summary files using healthcare service indicator code 35 for hospice and confirmed in the MAX Other Services files using CPT codes 651, 652, 655, and 656. Hospice length of stay was defined as the number of days children were enrolled in hospice care during the last calendar year of life. To construct this measure, each per diem hospice encounter for a child was identified and counted.

Independent variables. Using the *ICD-9* codes in the MAX Other Services files, a measure of MCCCs was created. The measure of MCCCs was dichotomized as whether a child had two or more complex chronic conditions. The referent group was one complex chronic condition.

Control variables. A group of covariates based on the Andersen Behavioral Model of Health Services Use was created *a priori*: predisposing, enabling, and need characteristics.[19] Predisposing characteristics are interpersonal factors that increase children's propensity to utilize healthcare services and included *gender*, *age*, *race*, and *ethnicity*. Enabling characteristics are accessible resources that promote healthcare utilization among children and their families, including additional *private insurance*, *usual source of care*, Medicaid-assigned *case management*, *pediatric hospice accessibility*, *and public policy* support for pediatric end-of-life care. Need characteristics describe the health status of children requiring healthcare services. For this study, children's diagnoses (i.e., *cancer*, *congenital*, *neurological*, *cardiovascular*), *psychological health status*, and *functional status* were measures of need for healthcare services.

Analytical strategy

Using pooled cross-sectional data, descriptive statistics were obtained for the study sample. Frequencies, means, and standard deviations were calculated. Separate multivariate analyses were conducted for hospice enrollment and hospice length of stay. A multivariate logistic regression with year fixed effects was conducted to examine the effect of MCCCs on hospice enrollment, which was reported as adjusted odds ratios (ORs).[20] A negative binomial model with year fixed effects was used to explore the relationship between MCCCs and hospice length of stay. This analytic model was appropriate for an estimation based on count data such as the number of hospice days.[20] A goodness-of-fit indicator was used to determine that the data fit a negative binomial distribution rather than a Poisson distribution for count data.[20] For this study, the negative binomial results were reported as adjusted incidence rate ratios (IRRs). Stata 11.0 software (StataCorp LP, College Station, TX) was used to conduct the statistical tests.

Results

Summary statistics for the variables included in the analytical model are shown in Table 1. Slightly more than 10% of children enrolled in hospice care with an average length of stay of approximately three days. In the study sample, 48.6% of the children had MCCCs. Over half the children were males (52.8%) and between 0 and 5 years was the most common age group (42.4%). A majority of children were non-Caucasian (82.8%) and 36.8% were Hispanic.

Over 13% of the children had private insurance in addition to their Medicaid coverage. It was common for children to have a usual source of care with a primary care provider (63.1%), while a third were assigned a Medicaid case manager. Over 80% of children resided within 10 miles of a pediatric hospice provider and 10% resided in a county where public policy offered palliative care support. Neurological complex chronic conditions were the most common (53.1%) and congenital complex chronic conditions were the least common (18.4%) in the sample. Almost a third of the children received treatment for psychological issues and over three-quarters had functional limitations.

Table 1. Descriptive Statistics of Study Variables (N= 2036)

Variables	N	*Percentage/Mean(SD)*
Dependent variables		
Hospice utilization		
Hospice enrollment	216	10.61
Hospice length of stay	2036	2.72 (16.77)
Independent variables		
Multiple complex chronic conditions	988	48.55
Covariates		
Gender		
Male	1075	52.80
Female	961	47.20
Age groups		
0–5 years	863	42.39
6–14 years	588	28.88
15–20 years	585	28.73
Race		
Caucasian	351	17.24
Non-Caucasian	1685	82.76
Ethnicity	750	36.84
Private insurance	269	13.21
Usual source of care	1284	63.06
Case management	595	29.22
Pediatric hospice accessibility	1639	80.50
Public policy	196	10.00
Diagnosis		
Cancer	588	28.88
Congenital	374	18.37
Neurological	1082	53.14
Cardiovascular	820	40.28
Psychological health status	568	27.90
Functional status	1607	78.93
Year 2007	498	24.46
Year 2008	527	25.88
Year 2009	531	26.08
Year 2010	480	23.58

The results of the multivariate regression analyses estimating the association between MCCCs and hospice utilization are presented in Table 2. MCCCs were not significantly related to hospice enrollment. However, children with MCCCs (IRR = 4.25, $p < 0.01$) were positively related to an increase in the number of days in hospice care. Compared with children with one complex chronic condition, the rate of hospice length of stay was almost four times higher for those children with MCCCs.

Several control variables were associated with hospice utilization. Having additional private insurance (OR = 0.28, $p < 0.001$) and a cardiovascular diagnosis (OR = 0.38, $p < 0.001$) were negatively associated with hospice enrollment, whereas a cancer diagnosis (OR = 2.41, $p < 0.001$) was related positively to hospice enrollment. Private insurance (IRR = 0.31, $p < 0.05$), accessibility to a pediatric hospice provider (IRR = 0.43, $p < 0.05$), and a cardiovascular diagnosis (IRR = 0.15, $p < 0.001$) decreased the number of days in hospice care. However, public policy support (IRR = 3.99, $p < 0.01$), along with cancer (IRR = 4.29, $p < 0.01$) and congenital (IRR = 3.19, $p < 0.05$) diagnoses, was related to an increase in the number of days children were enrolled in hospice. No other control variables were related to hospice utilization.

Discussion

The goal of this study was to examine the relationship between MCCCs and pediatric hospice utilization. Using longitudinal Medicaid claims data from California from 2007 to 2010, the effect of MCCCs on hospice enrollment and hospice length of stay was explored, while controlling for predisposing, enabling, and need characteristics of children and their families. The descriptive analysis revealed that 11% of children enrolled in hospice care for an average of three days. This finding was consistent with prior Medicaid studies of pediatric hospice utilization[21] and suggests low utilization among the sample.

In this analysis, children with MCCCs were no more likely to enroll in hospice than their counterparts with one complex chronic condition. Several studies have shown similar results between MCCCs and hospice enrollment.[13,14] A reason for this finding may be the complex care needs of these children at end of life. Children with MCCCs may have multiple providers from diverse subspecialities.[22] While these specialists may manage a portion of the care, they typically do not integrate care across the children's numerous providers.[23,24] Thus, no one specialist may take the responsibility to make the referral to hospice care.[25] Instead, families often become the primary caregivers, medical managers, and health system navigators for their children.[26,27] Families may be so overwhelmed with the care for their children with MCCCs that they are unaware of the child's prognosis.[28] It might also be that families are unaware of hospice services at end of life for their children. Additional research is needed to understand the barriers and facilitators to hospice enrollment among these children.

The study found that the presence of MCCCs was associated with longer stays in hospice care for children. The results revealed that children with MCCCs had a rate of hospice length of stay almost four times higher than their counterpart without multiple conditions. This finding was expected. It

Table 2. Association Between Multiple Complex Chronic Conditions and Hospice Utilization ($N = 2036$)

Variables	Hospice enrollment OR	Hospice enrollment 95% CI	Hospice length of stay IRR	Hospice length of stay 95% CI
Independent variables				
Multiple complex chronic conditions	1.26	(0.841–1.885)	4.25**	(1.624–11.11)
Covariates				
Female	1.07	(0.794–1.429)	1.08	(0.580–1.990)
Age 0–5 years	1.34	(0.903–1.981)	1.82	(0.711–4.651)
Age 6–14 years	0.97	(0.664–1.465)	1.06	(0.460–2.432)
Caucasian	1.22	(0.803–1.862)	0.98	(0.387–2.474)
Ethnicity	0.86	(0.615–1.207)	0.75	(0.375–1.511)
Private insurance	0.28***	(0.146–0.537)	0.31*	(0.116–0.828)
Usual source of care	1.07	(0.742–1.541)	0.79	(0.351–1.761)
Case management	0.88	(0.604–1.287)	0.66	(0.302–1.455)
Pediatric hospice accessibility	1.03	(0.703–1.498)	0.43*	(0.188–0.992)
Public policy	1.44	(0.907–2.287)	3.99**	(1.432–11.11)
Cancer	2.41***	(1.634–3.566)	4.29**	(1.637–11.24)
Congenital	1.21	(0.790–1.852)	3.19*	(1.228–8.295)
Neurological	1.33	(0.914–1.923)	2.17	(0.934–5.024)
Cardiovascular	0.38***	(0.252–0.566)	0.15***	(0.062–0.344)
Psychological status	0.98	(0.694–1.395)	0.47	(0.207–1.051)
Functional status	0.84	(0.558–1.274)	1.18	(0.448–3.099)
Year 2008	0.76	(0.487–1.180)	0.94	(0.369–2.397)
Year 2009	1.13	(0.746–1.708)	0.94	(0.373–2.396)
Year 2010	1.15	(0.752–1.770)	0.43	(0.162–1.148)

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.
OR, odds ratio; IRR, incident rate ratio; CI, Confidence Interval.

was anticipated that children with MCCCs would have longer stays in hospice care to manage pain and the other complex symptoms at end of life. Although many children with MCCCs have distinct disease patterns such as cancer and cardiovascular disease, our prior work has shown that almost a third of children at end of life have MCCCs with a wide range of possible combinations of complex chronic conditions.[17] Thus, children with MCCCs present with unique clinical challenges for end-of-life care in hospice and may benefit from an extended length of stay. For example, extra days or weeks in hospice may enable clinicians to conduct a thorough initial assessment, consult with the hospice team, assess medications, and provide other psychosocial services. It also suggests that there is time for clinicians to provide effective pain and symptom management or engage social work services or pastoral care. Utilizing hospice care for a longer time period maximizes the ability of hospice clinicians to deliver quality end-of-life care.

This study also explored confounding variables related to hospice utilization. The results revealed that additional private insurance was associated with hospice utilization. This was inconsistent with other researchers who found no relationship between two types of insurance and hospital admissions and ED visits for children with complex chronic conditions.[6] However, in this study, additional insurance was negatively related to hospice enrollment and length of stay for children with MCCCs. Among pediatric Medicaid beneficiaries, it is possible for children to be enrolled in Medicaid and have additional private insurance through their parents' health insurance plans. While private insurance is the primary payer and Medicaid is the secondary payer, care must be coordinated between the two plans.[29] Having two insurance plans often provides a financial benefit for families because more expenses might be covered by the two insurance plans. This reduces the families' out-of-pocket expenses. However, additional insurance also adds an administrative burden for families as they seek healthcare services in the final year of a child's life. Such families might need to obtain approval for hospice care services from one or both plans. Timing of approvals can vary between plans.[30] For families managing the decline in their child's health during the last year of life, coordinating benefits between insurance plans may not be a priority. Thus, the administrative burden of private insurance and Medicaid insurance for children with complex chronic conditions might be a hindrance to children obtaining hospice care. Future research is needed to explore the coordination-of-benefits issues between private insurance and Medicaid for families of children with complex chronic conditions, especially at end of life.

Limitations

There are important limiting factors to consider in the interpretation of the study. The study findings are only generalizable to the pediatric Medicaid population in California. The results might differ among children who reside in other states or countries. However, California has the largest number of pediatric Medicaid beneficiaries and is often the policy leader in end-of-life care.[31] The study also included data from only the last calendar year of life for children. It did not include a comprehensive claims history for children. As a result, the hospice length of stay may have been truncated or under-reported for some children. However, in this study, the average length of stay was only a matter of days, which makes it less likely that the hospice length of stay reported would be significantly truncated. Finally, this study was based on data between 2007 and 2010 for children with MCCCs. With the recent recognition that these conditions come under the rubric of hospice and palliative care, future research might examine the next cohort of children to see whether patterns change.

Conclusions

As one of the first studies of hospice utilization among children with MCCCs, this research contributes to our knowledge of end-of-life care for a special group of underserved children. This study demonstrated that children with MCCCs have limited use of hospice care at end of life. The results suggest that although MCCCs did not significantly influence hospice enrollment, there was a relationship between MCCCs and hospice length of stay. Future research is needed to explore barriers to hospice care for children with MCCCs.

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Disclosure Statement

No competing financial interests exist.

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