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End-of-life care for Hispanic children: A study of California Medicaid beneficiaries

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Abstract

Introduction—Over 8,000 Hispanic children die annually in the United States; yet, little is known about the end-of-life care utilized. The purpose of this study was to examine the children and family characteristics associated with end-of-life care for Hispanic children.

Methods—A sample of 370 Hispanic children was created, using the 2009-2010 California Medicaid data. The relationship between child and family characteristics and end-of-life care utilization (i.e., hospice enrollment, emergency room utilization, hospital admissions) was analyzed using multivariate regression.

Results—Pediatric hospice accessibility ($p < 0.05$), palliative care policy ($p < 0.01$), congenital anomalies ($p < 0.01$), and cardiovascular conditions ($p < 0.01$) were related to hospice enrollment. Usual source of care ($p < 0.001$), functional status ($p < 0.001$), palliative care policy ($p < 0.01$), and private insurance ($p < 0.01$) were associated with emergency room utilization; while usual source of care ($p < 0.001$), cancer ($p < 0.001$), and disability status ($p < 0.01$) corresponded with hospital admissions.

Conclusion—Nursing practices aimed at engaging Hispanic families in their community are critical to end-of-life care utilization for Hispanic children.

Keywords

end-of-life care; Hispanics; pediatrics; hospice care; emergency room; hospital admissions

Introduction

The Hispanic population in the United States (US) is the nation's largest minority group with projections of double digit growth. The overall Hispanic population is expected to double by 2050 and the percent of Hispanic children in the population is anticipated to increase from the current 24% to 32% (Ennis & Albert, 2010; Ortman & Guarneri, 2009).

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However, 8,000 or 20% of children who die annually in the US are Hispanics and many have life-limiting health conditions (Osterman et al., 2015; US Department of Health and Human Services Centers for Disease Control and Prevention, 2013). As the Hispanic population continues to increase, it is imperative to understand the end-of-life care utilized by this population, in order to ultimately ensure quality end-of-life care is delivered to Hispanic children and their families.

The evidence, however, about the end-of-life care including hospice, emergency room, or inpatient care utilized by Hispanic children and their families is sparse. Reports of pediatric hospice use have shown that Hispanic children are the least likely to enroll in hospice care at end of life, compared to other ethnicities (Knapp et al., 2009), and when Hispanic children do enroll in hospice, they often represent a small percent of children in hospice care (Lindley & Shaw, 2014; Thienprayoon et al., 2015). Conversely, studies have shown that Hispanic children frequently visit the emergency room for health care with multiple hospital admission, even at end of life (Cabey et al., 2014; Rasooly et al., 2014; Simon et al., 2010). However, the characteristics of Hispanic children and their families that may affect end-of-life care utilization have not been studied. For example, community is important in the Hispanic culture and Hispanic families might be more likely to enroll in pediatric hospice care if there is a pediatric hospice provider in their community (O'Mara & Zborovskaya, 2016). Additionally, Hispanic children with a usual source of pediatric primary care might not access the emergency room, if they have an accessible pediatrician for urgent care needs even at end of life. Thus, the characteristics of the children and family may provide important insight into the care utilized at end of life.

Understanding end-of-life care for Hispanic children and their families is critical for nurses and other clinicians. There is a need to ensure culturally competent, high-quality end-of-life care for diverse children (O'Mara & Zborovskaya, 2016; Periyakoil, Neri, & Kraemer, 2015; Thienprayoon et al., 2015). Improving our knowledge of the characteristics of children and their families that influence end-of-life care utilization will assist nurses, other clinicians, and policy makers to address the specific needs of Hispanic children, while ensuring children and their families receive quality end-of-life care. Therefore, the purpose of this study was to examine the children and family characteristics associated with end-of-life care for Hispanic children.

Methods

Study Design and Sample

A retrospective, cohort design was conducted with Center of Medicare and Medicaid Services (CMS) Medicaid data to examine children and family characteristics associated with end-of-life care utilization among Hispanic children. The sample consisted of children identified by health care providers as Hispanic ethnicity from the Medicaid claims payment data. Children were defined as less than 1 to 20 years. Children were included in the study if they died between January 1, 2009, 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) based on the International

Classification of Diseases, 9th revision (ICD-9) codes as recommended by Feudtner and colleagues (Feudtner, Christakis, & Connell, 2000; Feudtner et al., 2001). Children were excluded from the study if they had missing entries, were non-California residents, or participated in Medicaid managed care plans. After applying the inclusion and exclusion criteria, the final sample was 370 Hispanic children. The study was approved by the Institutional Review Board of the University of Tennessee, Knoxville.

Data Sources

The main data source was the 2009 and 2010 California Medicaid claims files (Medicaid Analytic Extract [MAX]). The Medicaid Person Summary files provided demographic and health status information, and the MAX Other Services files provided procedure codes for health care services and ICD-9 diagnosis codes. The California Office of Statewide Health Planning and Development State Utilization Data File of Home Health Agency and Hospice Facilities from fiscal year 2009 and 2010 were also used. They contained the addresses of pediatric hospice providers which were used to construct the geographic measure of hospice accessibility. Information was provided by the Children's Hospital Association on the location of children's hospitals in California and was used to create the measure of hospital accessibility. Data on the counties that offered public policy support for pediatric end-of-life care (i.e., Nick Snow Children's Hospice and Palliative Care Act of 2006) was from the California Department of Health Care Services-Partners for Children. All data were manually merged by Federal Information Processing Standards (FIPS) code to create a comprehensive data set for this study.

Measures

Dependent variables—Three measures of end-of-life care were developed for this study. The first measure was *hospice enrollment*, which was defined as whether or not a child enrolled in hospice care during the last calendar year of life (Lindley & Nageswaran, 2015; Lindley & Shaw, 2014). Data were obtained from the MAX Personal Summary Record using the 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 *emergency room utilization*. This was operationalized as whether or not a child used emergency room services during the last calendar year of life. Procedure codes (99281, 99282, 99283, 99284, 99285) from the MAX Record files were used to create this variable. The third measure was *hospital admissions*. It was defined as whether or not the child was admitted to the hospital three or more times in the last calendar year of life. Information used to create this variable was from the MAX Personal Summary Record count of total inpatient stays in the calendar year.

Independent variables—A group of children and family characteristics based on the Andersen Behavioral Model of Health Services Use was created-priori for this study that included predisposing (i.e., gender, age), enabling (i.e., hospice accessibility, hospital accessibility, usual source of care, public policy support, private insurance coverage), and need characteristics (i.e., diagnoses, health status) (Andersen, 1968; Lindley, 2015). *Gender* was defined as male or female. The *age* of the child was categorized as less than 1 year to 5 years, 6 to 14 years, and 15 to 20 years. *Hospice accessibility* was operationalized as

whether or not a child and their family resided within 10 miles of a pediatric hospice provider and was created with mapping software (ArcGIS Online). A measure of *hospital accessibility* was whether or not a children's hospital was present in the family's county of residence. *Usual source of care* was whether or not a child was an established patient with a primary care provider. *Public policy support* was defined as whether the family resided in a county covered by the California Palliative Care Waiver allowing a child to receive concurrent curative and hospice care. Whether or not a child had private health insurance along with the Medicaid coverage was the measure of *private insurance coverage*. Separate variables were created for the diagnosis categories *cancer*, *congenital* (e.g., chromosomal anomalies, genetic defects), *neurological* (e.g., moderate and severe intellectual disabilities, cerebral palsy, epilepsy), and *cardiovascular* (e.g., heart and valve malformations, cardiomyopathies). Variables were also created for the health status indicators: *disability health status* (whether the child was eligible for Medicaid coverage because of disability status), *psychological health status* (whether the child received any psychiatric care), and *functional health status* (whether the child received durable medical equipment, transportation services, personal care, or occupational therapy/physical therapy).

Data Analysis

Descriptive statistics were calculated for Hispanic children and families in the sample using pooled, cross-sectional data. Bivariate analyses were conducted to test statistical assumptions and examine multicollinearity among the study variables. No evidence of multicollinearity was found. Multivariate regressions were conducted to evaluate the relationship between children and family characteristics and end-of-life care. Separate analyses were conducted for hospice enrollment, emergency room utilization, and hospital admissions. A logistic regression model was appropriate to estimate the relationships because of the binary nature of the outcome variables (Long & Freese, 2014). The multivariate analyses are presented as adjusted odds ratios (OR) and 95% confidence intervals. All analyses were conducted using Stata 11.0 (StataCorp LP, College Station, TX) and ArcGIS Online (ESRI Inc., Redlands, California).

Results

Demographic Characteristics

Sample summary statistics are shown in Table 1. Over 10% of Hispanic children, who died with a complex chronic condition, enrolled in hospice care. Over half of the sample (51.6%) utilized the emergency room in their last year of life and almost a third (28.9%) had three or more hospital admissions. Males (57.6%) and the age group 15 to 20 years (35.7%) were most common. A majority of the children and families had access to pediatric hospice (78.1%), children's hospital (63.2%), and a usual source of care (63.0%). Over 16% of children and families lived in counties covered by public policy support for palliative care, while 11.4 % had additional private insurance coverage. The most common diagnosis was neurological (53.2%) and the least common was congenital (17.6%). Children in the study were generally classified as disabled under Medicaid (89.7%) with reduced functional status (82.2%), while a third had a diminished psychological health status (30.8%).

Relationship of Factors to End-Of-Life Care Utilization

The results of the logistic regression to predict hospice enrollment appear in Table 2. The odds of enrolling in hospice care were almost 5 times higher for Hispanic children who had access to a pediatric hospice provider (OR = 4.82, 95% CI = 1.23-18.93), compared to those who did not. Hispanic children and families who resided in a county with public policy support for palliative care had significantly greater odds of enrolling in hospices (OR = 3.59, 95% CI = 1.42-9.06), compared to children who resided in non-palliative care counties. The odds of hospice enrollment were also significantly higher for Hispanic children with congenital anomalies (OR = 3.14, 95% CI = 1.32-7.45) than children without this condition. Hispanic children with cardiovascular conditions versus those without cardiovascular conditions had lower odds of enrolling in hospice care (OR = 0.28, 95% CI = 0.11-0.72). No other characteristics were related to hospice enrollment.

The multivariate emergency room utilization model is shown in Table 3. Hispanic children with a usual source of care versus those without (OR = 2.92, 95% CI = 1.70-5.02) and reduced functional status compared to those without (OR = 3.74, 95% CI = 1.73-8.11) had increased odds of using the emergency room. However, Hispanic children with public policy support (OR = 0.50, 95% CI = 0.26-0.97) and private insurance coverage (OR = 0.30, 95% CI = 0.13-0.70) were negatively associated with emergency room utilization, compared to those children and families without these resources. No other characteristics of Hispanic children and families were related to emergency room utilization.

The analysis of children and family characteristics and hospital admissions is presented in Table 4. The odds of three or more hospital admissions in the last calendar year of life was three times higher for Hispanic children with a usual source of care (OR = 3.74, 95% CI = 1.84-7.61) and four times higher with a cancer diagnosis (OR = 4.54, 95% CI = 2.45-8.41), compared to children without a usual source of care or those lacking a cancer diagnosis. The odds of disabled, Hispanic children being admitted to the hospital three or more times was seven times higher (OR = 7.35, 95% CI = 1.66-32.60) than their counterparts without a disability classification. No other characteristics were associated with hospital admissions.

Discussion

The goal of the study was to examine the relationship between Hispanic child and family characteristics and end-of-life care utilization. From the descriptive analysis, end-of-life care varied between hospice utilization, emergency room visits, and multiple hospital admissions. Each type of end-of-life care exhibited unique patterns of child and family predictors. Thus, this analysis presented a novel way of understanding the end-of-life experience among Hispanic children and their families.

Among the children in the study, less than 11% utilized hospice care, which was consistent with the literature (Knapp et al., 2009). However, the multivariate analysis revealed that accessible pediatric hospice care providers in the community and public policies that promote pediatric end-of-life care in the community positively affected hospice utilization. In a recent study by Thienprayoon and colleagues (2016) of English- and Spanish-speaking families' experiences with pediatric hospice care, Spanish speakers stressed the importance

of being at home and concerns about geographic separation from the family. The Hispanic culture is grounded in the community and family. Family and neighbors interact to create a sense of community with shared language and cultural values. It is important for the Hispanic family to have community access to end-of-life care resources for that feeling of belonging, while ensuring that their family receives quality end-of-life care (O'Mara & Zborovskaya, 2016). In addition, in many Hispanic families both parents work and have limited or no transportation. This situation makes it difficult to utilize end-of-life care outside the community. Thus, resources in the Hispanic community that enable children and families to access to pediatric end-of life-care may support Hispanic families' decisions to utilize hospice care at end of life (Periyakoil et al., 2015). Although the data did not permit an exploration of Hispanic culture, language, and religiosity, these factors may enable and support Hispanic families to bring their children home at end of life. Additional research is needed to examine the role of community and family enablers in assisting Hispanic families to use pediatric hospice care.

In this analysis, children with a usual source of care were less likely than their counterparts without a usual source of care to visit the emergency room and have multiple hospital admissions. More specifically, being an established patient with a primary care provider was associated with intensive end-of-life care in the acute care setting. This was contrary to expectations. The primary care literature suggests that access to a primary care provider reduces emergency room visits and inpatient care because the primary care provider can identify and respond to health problems through phone calls or clinic visits (Knapp et al., 2012). Using data from 90,512 children enrolled in California, Massachusetts, and Texas Medicaid, Tyo and colleagues (2013) found that pediatric primary care providers influenced emergency room visits and hospitalizations. Kronman and colleagues (2008) reported similar results in their study of Medicare beneficiaries at end of life. And yet, in this sample Hispanic children and their families were more likely to use the emergency room and have multiple hospital admissions given their access to primary care. A possible reason for these findings might be the availability of critical care in the emergency room and hospital. As the child stops responding to treatment at end of life, many families want care when their child is having an acute episode, whether it be 2am or on Sunday. The hospital and emergency room are open around-the-clock to provide that immediate care. Additionally, Hispanic children represent one of the fastest growing populations of children using the emergency room and inpatient hospital care and this may also be the case at end of life (Cabey et al., 2014; Rasooly et al., 2014; Simon et al., 2010). Future research is warranted to explore the accessibility of primary care providers and how they might reduce emergency room and multiple hospital admissions among Hispanic children and their families.

The study has several limitations to consider, similar to other studies that have relied on administrative data. First, there is the possibility of underreporting of ethnicity. The MAX files capture the ethnicity of patients through patient and/or family identification in the Medicaid administrative paperwork. Some patients and families may not wish to disclose their ethnicity, especially if there are any concerns about undocumented status in the family. Second, the MAX did not include information on the type of Hispanic ethnicity. The Hispanic culture is made up of many different groups such as Puerto Rican, Mexican, Colombian, Mayan, and other Central American ethnic groups. Some groups, such as

Mayans, do not speak Spanish. Thus, the data lack specificity in the measurement of Hispanic. Third, there may be omitted variable bias in the study. As an example, the database did not include information on acculturation. Acculturation is a process by which a person modifies their habits and values based on how long they have resided in the US might impact their end-of-life care choices. Fourth, children in the sample had a variety of health conditions. These medical conditions have difference disease trajectories towards end of life that might influence family decisions on what care to access for their children. However, the children in the study were all classified as having a complex chronic condition, which studies have shown are life-limiting illnesses (Feudtner et al., 2000; 2001). Finally, the study was conducted with California Medicaid data that limits the generalizability of the findings to other states. California, however, has the largest population of Hispanic residents and is a leader in hospice care by implementing new and emerging pediatric end-of-life care services before they are adopted in other states (Ennis & Albert, 2010; Dabbs, Butterworth, & Hall, 2007). As such, exploring end-of-life use among Hispanic children and their families in California may provide important insight into pediatric Hispanic end-of-life use for other states and the nation.

Conclusions

This study provides an examination of the relationship between children and family characteristics and end-of-life care utilization among Hispanic children. Almost 11% of children in the sample utilized hospice care in their last calendar year of life. Community access to pediatric hospice care providers and public policies that promote pediatric end-of-life care in the community positively affected hospice utilization among Hispanic children and their families. The importance of community in the Hispanic family was reinforced in this study. Policies and practices aimed at engaging Hispanic families in their community are critical to accessing end-of-life care for Hispanic children. The results revealed that over half of the Hispanic children visited the emergency room and nearly a third of children were admitted 3 or more times to the hospital in their last calendar year of life. Hispanic children with a usual source of primary care were significantly more likely to visit the emergency room and to be admitted multiple times to the hospital. Additional research into the role of primary care clinicians is necessary to better understand their accessibility in providing primary care for Hispanic children and families at end of life.

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Table 1

Descriptive Statistics of Study Variables (N=370)

Variables	N	Percentage
Dependent Variables		
Hospice Enrollment	40	10.81
Emergency Room Utilization	191	51.62
Hospital Admissions	107	28.92
Independent Variables		
Gender		
Male	213	57.57
Female	157	42.43
Age		
< 1 to 5 years	130	35.14
6 to 14 years	108	29.19
15 to 20 years	132	35.68
Hospice Accessibility	289	78.11
Hospital Accessibility	234	63.24
Usual Source of Care	233	62.97
Public Policy Support	62	16.76
Private Insurance Coverage	42	11.35
Diagnosis		
Cancer	126	34.05
Congenital	65	17.57
Neurological	197	53.24
Cardiovascular	148	40.00
Health Status		
Disability Status	332	89.73
Psychological Status	114	30.81
Functional Status	304	82.16

Table 2

Results of Logistic Regression for Hospice Enrollment (N=370)

Variables	OR	95% CI
Gender		
Male	(ref)	
Female	0.59	0.28-1.26
Age		
< 1 to 5 years	(ref)	
6 to 14 years	1.07	0.40-2.83
15 to 20 years	0.76	0.29-2.01
Hospice Accessibility	4.82 *	1.23-18.93
Hospital Accessibility	0.72	0.32-1.65
Usual Source of Care	1.23	0.51-2.99
Public Policy Support	3.59 **	1.42-9.06
Private Insurance Coverage	0.21	0.03-1.68
Diagnosis		
Cancer	1.88	0.82-4.31
Congenital	3.14 **	1.32-7.45
Neurological	1.11	0.50-2.44
Cardiovascular	0.28 **	0.11-0.72
Health Status		
Disability Status	2.25	0.47-10.66
Psychological Status	0.91	0.41-2.02
Functional Status	3.59	0.69-18.58

Note: OR, odds ratio; CI, Confidence Intervals.

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

Table 3

Results of Logistic Regression for Emergency Room Utilization (N=370)

Variables	OR	95% CI
Gender		
Male	(ref)	
Female	1.11	0.70-1.78
Age		
< 1 to 5 years	(ref)	
6 to 14 years	0.67	0.36-1.27
15 to 20 years	1.06	0.58-1.92
Hospice Accessibility	1.05	0.55-1.98
Hospital Accessibility	1.02	0.60-1.74
Usual Source of Care	2.92 ***	1.70-5.02
Public Policy Support	0.50 **	0.26-0.97
Private Insurance Coverage	0.30 **	0.13-0.70
Diagnosis		
Cancer	0.88	0.51-1.53
Congenital	0.73	0.39-1.35
Neurological	1.10	0.65-1.85
Cardiovascular	1.30	0.77-2.19
Health Status		
Disability Status	1.03	0.47-2.24
Psychological Status	1.14	0.67-1.92
Functional Status	3.74 ***	1.73-8.11

Note: OR, odds ratio; CI, Confidence Intervals.

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

Table 4

Results of Logistic Regression for Hospital Admissions (N=370)

Variables	OR	95% CI
Gender		
Male	(ref)	
Female	0.87	0.51-1.48
Age		
< 1 to 5 years	(ref)	
6 to 14 years	0.61	0.29-1.26
15 to 20 years	0.62	0.31-1.22
Hospice Accessibility	1.06	0.51-2.18
Hospital Accessibility	0.93	0.51-1.69
Usual Source of Care	3.74 ***	1.84-7.61
Public Policy Support	0.80	0.37-1.73
Private Insurance Coverage	0.79	0.30-2.07
Diagnosis		
Cancer	4.54 ***	2.45-8.41
Congenital	1.28	0.64-2.54
Neurological	1.26	0.70-2.25
Cardiovascular	1.75	0.97-3.16
Health Status		
Disability Status	7.35 **	1.66-32.60
Psychological Status	1.52	0.86-2.66
Functional Status	2.89	0.98-8.55

Note: OR, odds ratio; CI, Confidence Intervals.

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