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Home care for children with multiple complex chronic conditions at the end of life: The choice of hospice versus home health

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Abstract

Families desire to bring their children home at end of life, and this creates a variety of unique care needs at home. This study analyzed the child and family factors associated with hospice versus home health care use in the last year of life among children with multiple complex chronic conditions. Using the Andersen Behavioral Healthcare Utilization Model, predisposing, enabling, and need factors of the child and family were shown to be significant predictors of hospice and home health care use. Hospice and home health care have advantages, and families may wish to use the service that best fits their needs.

INTRODUCTION

Children with medical complexities are a growing population within the 40,000 children who die in the United States (US) each year (Osterman, Kochanek, MacDorman, Strobino, & Guyer, 2015). Many of these children have multiple complex chronic conditions (MCCC) with multisystem diseases, technology dependence, and complex medication regimens that become more profound as they come to the end of their lives (Feudtner, Christakis, & Connell, 2000; Lindley & Lyon, 2013). It is estimated that MCCC children account for a significant portion of the US health care spending with expenditures reaching \$110 billion annually (Cohen et al., 2012; Lassman, Hartman, Washington, Andrews, & Catlin, 2014). Although most children spend their last days in an acute care setting (Cawkwell, Gardner, & Weitzman, 2015), families increasingly desire to bring their children home at end of life (Kassam, Skiadaresis, Alexander, & Wolfe, 2014). These children often require a high level of medical care and technological support, even at end of life (Srivastava, Stone, & Murphy,

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2005). This situation creates a variety of unique care needs at home, including the need among many families for complex, medically intensive care.

Hospice and home health care are generally the two care models available for families who want home care at end of life for their children with MCCC (Institute of Medicine, 2014). Hospice care, with its expertise in pain and symptom management, availability for urgent needs and escalating end-of-life symptoms, and array of family-centered services ranging from spiritual care to bereavement, offers an established model for high quality end-of-life care. Home health, however, offers the option of skilled nursing care, which may be especially important for families of MCCC children with intensive daily needs and medical technology such as ventilators and feeding tubes in the home (Senft, 2011).

There is little published data on hospice and home health care. Little is known about the MCCC children admitted to home health or hospice care, or what determines which end-of-life care service they use. Previous literature has largely focused on differences in organizational factors (Gross, Peek-ASA, Nocera, & Casteel, 2013; Parker-Lee & Decker, 2010; Resnick, Hickman, & Foster, 2012) and differences in patient outcomes between hospice and home health care (Randall-David, Wright, Porterfield, & Lesser, 2003; Resnick et al., 2012; Weber, Brown, Huslage, Sickbert-Bennett, & Rutala, 2009). And yet, additional factors may influence this decision, including attributes of the child and his or her illness (e.g., child age, diagnosis, functional status, and disability), family and neighborhood sociodemographic factors (e.g., race, ethnicity, and household income), and care referral sources (e.g., access to pediatric hospitals and a regular primary care physician, and use of a case manager).

Understanding the child and family factors that influence the use of hospice versus home health care is both timely and relevant. The Affordable Care Act (ACA) now allows for concurrent curative and palliative care for MCCC children, and some states including California anticipated this need by creating similar provisions in advance of the ACA. However, this important step still does not fully expand services available within pediatric hospice to the level of home care that may be needed by some families. As such, select families may continue to opt for home nursing without hospice for their MCCC children, a choice that may improve access to substantial nursing support in the home, but leave such families without adjunctive services such as bereavement support and access to social workers and chaplains. Furthermore, improving knowledge of MCCC children admitted to these care models may inform clinical practice and ultimately improve the quality of end-of-life care for children and their families. Therefore, in order to better understand the health care choices of families with MCCC children, the purpose of this study was to analyze the child and family factors associated with hospice versus home health care use at end of life.

METHODS

Study Design and Sampling

This study was a retrospective cohort study of hospice and home health use from 2007 to 2010. The eligibility criteria for the study included children between the ages of 0 to 20 years, who died between January 1, 2007 and December 31, 2010, and were enrolled in the

California Medicaid program for any part of their last year of life. California was chosen because it has the largest number of pediatric Medicaid beneficiaries (Kaiser Family Foundation, 2010). Inclusion criteria included having two or more complex chronic conditions (Feudtner et al., 2000). Exclusion criteria included non-California residence and missing data. The final sample size was 989 pediatric decedents. This study was reviewed and approved by the University of Tennessee at Knoxville Institutional Review Board.

Data Sources

Multiple data sources were used for this study. A pooled, cross-sectional database from the 2007 to 2010 California Medicaid program's *Medicaid Analytic Extract* files was used. The *Medicaid* files include individual records for beneficiaries enrolled in the California Medicaid program (Hennessy, Leonard, Palumbo, Newcomb, & Bilker, 2007), which include demographics, eligibility information, summary claims, payment data, and detail data on services and diagnoses. These data are administered by the Centers for Medicare and Medicaid Services. Data from the California Department of Health, Partners for Children Agency provided information 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). Information on the location of children's hospitals in California was provided by the Children's Hospital Association. The 2007 to 2010 California Office of Statewide Health Planning and Development's (CA OSHPD) *State Utilization Data File of Home Health Agencies and Hospice Facilities* were also used. These files contained information on hospice agencies.

Measures

Dependent Variable—To identify children who utilized home care in their last calendar year of life, the Medicaid Personal Summary and Other Services records were used. A categorical measure of home care was created: no home care, hospice use, and home health care use. Children who used both hospice and home health care were included in the group who used hospice care because their number was less than ten.

Independent Variables—A group of covariates were created a-priori based on the Andersen Behavioral Healthcare Utilization Model (i.e., predisposing, enabling, need) and previous literature examining hospice and home health use (Babitsch, Gohl, & von Lengerke, 2012; Lindley, 2015). Age at death was categorized as less than 5 years, 6 to 14 years, and 15 to 20 years. A binary variable for gender (0 = male, 1 = female) was created. Race was operationalized as Caucasian, other (African American, Asian, Pacific Islander) or unspecified, and ethnicity was whether or not the child was Hispanic. Usual source of care was operationalized as whether the child was an established patient with a pediatric primary care provider. Hospice accessibility was defined as residing within 10 miles of a hospice that provided care for children (Jenkins, Chapman, Harshbarger, Townsend, 2009). Using pediatric hospital address data from Children's Hospital Association, along with children's residence information in the Medicaid file, a measure of pediatric hospital accessibility was created. It was defined as whether or not a children's hospital was present in the child's county of residence. Average household income above \$50,000/annual per zip code of residence was a measure of neighborhood socio-economic status. Public policy support was

defined as whether the child resided in a county covered by the California Palliative Care Waiver, which allowed for concurrent curative and palliative care. Case management was operationalized as whether a child had an assigned Medicaid case manager. Separate variables were created for the child's diagnosis: cancer, congenital anomalies (e.g., chromosomal anomalies, genetic defects), cardiovascular conditions (e.g., heart and valve malformations, cardiomyopathies), intellectual disabilities (e.g., moderate and severe intellectual disabilities), cerebral palsy, and epilepsy. Whether the child was eligible for Medicaid coverage because of their disability status was a measure of disability status. Psychological status was measured by whether the child received psychiatric care. Functional status was defined as whether the child needed durable medical equipment, transportation services, personal care, or occupational therapy/physical therapy.

Statistical Analysis

The primary aim of the study was to examine child and family factors associated with hospice versus home health care use among MCCC children. Descriptive statistics were used to describe the children in the sample. The Pearson chi-square test for differences in proportions and *t*-test for difference in means were used to provide comparisons of children who used hospice versus home health care. The results are presented in the form of univariate distributions. Multinomial logistic regression was used to estimate the child and family factors related to hospice and home health care use. This model was preferred because the home care outcome (no home care, hospice care, home health care) was categorical and unordered (Long & Freese, 2006). The results were reported as relative risk ratios (RRR). All analyses were conducted using Stata 11.0 (StataCorp LP, College Station, TX) and ArcGIS Online (ESRI Inc., Redlands, California).

RESULTS

Summary statistics for the study variables are shown in Table 1. Almost 12% of children used hospice, 24% used home health care, and 64% did not seek home services in the last year of life. In the overall sample, children with MCCC were commonly less than 5 years old (49.3%) with an unspecified race (76.0%). Over a third (39.0%) of MCCC children were Hispanic. It was common for children to have a usual source of primary care (73.5%) and a hospice within 10 miles of their residence (82.0%). Most MCCC children had access to a pediatric hospital in their community (64.0%). Ten percent of children resided in a county with public policy support for end-of-life care and 29% had a case manager. Cardiovascular conditions were the most frequent health condition (61.5%). MCCC children in the sample had diminished disability (91.4%) and functional status (82.5%).

A comparison of the child and family factors between MCCC children who used hospice versus home health showed several significant differences (Table 1). MCCC children who used home health care were typically less than 5 years of age (55.9% vs. 44.8%) and had a usual source of care (93.3% vs. 78.5%). They commonly suffered from congenital anomalies (39.1% vs. 28.5%) or cardiovascular conditions (65.1% vs. 41.4%). Home health care children had diminished functional status (97.5% vs. 90.5%), compared to hospice care

children. No other significant differences existed among factors between hospice and home health children.

The results of the multinomial regression analysis, estimating the association between child and family factors and hospice use, are presented in Table 2. A cardiovascular diagnosis was negatively associated with hospice use ($RRR = 0.43, p < 0.001$); whereas diminished functional status was positively related to hospice use ($RRR = 2.47, p < 0.05$). No other covariates were related to hospice use.

Several child and family factors were also associated with home health care use (Table 2). MCCC children 6 to 14 and 15 to 20 years were negatively associated with home health care use ($RRR = 0.57, p < 0.05$ and $RRR = 0.48, p < 0.01$ respectively), compared to children less than 5 years. Children with a usual source of primary care significantly were associated with home health care use ($RRR = 4.47, p < 0.001$). In addition, access to a pediatric hospital ($RRR = 1.53, p < 0.05$) and diminished functional status ($RRR = 7.90, p < 0.001$) were positively related to home health care use. No other factors were associated with home health care use.

DISCUSSION

The goal of the study was to examine the association between child and family factors and hospice versus home health care use. Home care use at end of life among children with MCCC was low. About 24% of the children used home health care and fewer than 12% ever used hospice care in the last year of life. In a white paper produced by the Children's International Project on Palliative/Hospice Services (ChiPPs) for the National Hospice and Palliative Care Organization (NHPCO), experts in the field of pediatric, end-of-life care reported that less than 10% of dying children received hospice care (National Hospice and Palliative Care Organization, 2001). Others have drawn similar conclusions in studies of children with cancer and acquired immune deficiency syndrome (Klopfenstein, Hutchinson, Clark, Young, & Ruymann, 2011; Lyon et al., 2008). Given the role of hospice in provision of support and symptom management at end of life in the home care setting, these findings raise the possibility of missed opportunities for supportive care at end of life for these medically complex children.

This study found that several predisposing, enabling, and need factors of the child and family were significant predictors of home health care use. It was interesting to note that access to a children's hospital was related to home health care use. Given that most hospitals, including children's hospitals, have an affiliation or relationship with a home health care agency, it is not surprising that access to a pediatric hospital was related to home health care use at end of life (Lindley, Mark, & Lee, 2009). Unlike pediatric hospice care, there is a plethora of home health agencies available to provide home care for MCCC children (Lindley et al., 2013; National Association for Home Care & Hospice, 2011). These resources are generally well-known and well-used by hospital discharge planners and social workers in the discharge process (Cesta, 2014). As noted, home health care also offers important advantages, including familiar providers who may have worked with MCCC

children for years. As a result, families may be reluctant to transition to new, hospice care providers at the end of life.

Another interesting finding was the relationship between child age and home health care use. This study revealed that children over 6 years of age were less likely to use home health care. One possible explanation is children over the age of 6 years may not be home bound even at end of life. For children who are able to attend school, they may no longer qualify as homebound. Additionally, they may not need 24 hour a-day care and meals at home, if they are in school. Although the study could not explore reasons for using or not using home health care, the strong desire to interact with friends and teachers may disqualify them from home health care services because they are not homebound. Future research might examine what school-based health care services are available for MCCC children at end of life.

This analysis raises additional questions. First, what was the experience of children and families under each model? It is unclear whether families of children under hospice had all of their home care needs met, or whether they were left providing more daily care than they were prepared to provide. Similarly, it is unknown whether symptom management at the end of life was different for those under home health versus hospice, and whether families under home health received the help they needed in the days and hours before death, as well as in bereavement. It is also not known where these children died, and whether each service delivery model allowed for death in the place of the family's choosing. Finally, what is the right model for home care delivery for children at the end of life? Both systems have gaps in service delivery. In the best case, no family would have to choose between intensive symptom management and daily care needs. The sample was too small to fully evaluate the role of public policy support; the concurrent care model therefore needs ongoing exploration to determine its effects on home care delivery at the end of life.

There are several limitations of this study. Selection bias is a potential limitation in the Medicaid data set, which includes only children enrolled in fee-for-service Medicaid. The findings may not be generalized to managed care Medicaid beneficiaries or those outside of California. However, California often has health care practices, patterns, and policies that are influential nationally, and has been a leader in hospice care by implementing new and emerging pediatric end-of-life care services before they are adopted in other states (Dabbs, Butterworth, Hall, 2007). The data set included the last calendar year of life for the children enrolled in Medicaid and did not include a comprehensive claims history for MCCC children in the study. There may be other confounding factors that are related to hospice and home health care use that were not reflected in the study such as whether the children received a palliative care consultation.

Overall, there is no single "right" choice for end-of- life care for MCCC children. Both hospice and home health care services have advantages, and individual families may wish to use the service that best fits their needs. However, just as each service has advantages, each also leaves potential gaps in care for dying MCCC children, making the choice of service one that could profoundly impact experiences of care at the end of life for MCCC children and their families. The findings highlight the diverse circumstances of MCCC children in their last year of life. Although this study was able to identify factors associated with use of

hospice versus home health care, these findings are not intended to favor either model of home care delivery. Rather, the ideal circumstance is flexibility of services to meet the different needs of MCCC children and families. More work is needed to understand how home care can offer the highest quality care for MCCC children nearing the end of life.

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Table 1

Sample characteristics hospice versus home health care use (N=989)

	Total N=989	Hospice Care N=116	Home Health Care N=238	
Variables	n (%)	n (%)	n (%)	p-Value
Independent Variable				
Age				
<1 to 5 years	488 (49.3%)	52 (44.8%)	133 (55.9%)	.05 *
6 to 14 years	258 (26.1%)	35 (30.2%)	58 (24.4%)	.24
15 to 20 years	243 (24.6%)	29 (25.0%)	47 (19.7%)	.25
Female	490 (49.5%)	61 (52.6%)	134 (56.3%)	.51
Race				
Caucasian	121 (12.2%)	21 (18.1%)	28 (11.8%)	.11
Other	117 (11.8%)	##	##	##
Unspecified	751 (76.0%)	84 (72.4%)	188 (79.0%)	.17
Hispanic	386 (39.0%)	39 (33.6%)	86 (36.1%)	.64
Usual Source of Care	727 (73.5%)	91 (78.5%)	222 (93.3%)	.001 ***
Hospice Accessibility	881 (82.0%)	99 (85.3%)	187 (78.6%)	.13
Pediatric Hospital Accessibility	633 (64.0%)	67 (57.8%)	160 (67.2%)	.08
Neighborhood Socio-Economic	0.39 (0.14)	0.41 (0.15)	0.40 (0.14)	.32
Public Policy Support	88 (10.0%)	18 (15.5%)	##	##
Case Management	282 (28.5%)	35 (30.2%)	85 (35.7%)	.30
Diagnosis				
Cancer	372 (37.6%)	53 (45.7%)	87 (36.6%)	.10
Congenital Anomalies	322 (32.6%)	33 (28.5%)	93 (39.1%)	.05 *
Cardiovascular Conditions	608 (61.5%)	48 (41.4%)	155 (65.1%)	.001 ***
Intellectual Disabilities	171 (17.3%)	22 (19.0%)	47 (19.8%)	.86
Cerebral Palsy	208 (21.0%)	25 (21.6%)	67 (28.2%)	.18
Epilepsy	210 (21.2%)	25 (21.6%)	63 (26.5%)	.32
Disability Status	904 (91.4%)	103 (88.8%)	222 (93.3%)	.15
Psychological Status	368 (37.2%)	44 (37.9%)	118 (49.6%)	.04 *
Functional Status	816 (82.5%)	105 (90.5%)	232 (97.5%)	.004 **
Year 2007	225 (22.8%)	21 (18.1%)	61 (25.6%)	.12
Year 2008	287 (29.0%)	28 (24.1%)	70 (29.4%)	.50
Year 2009	266 (26.9%)	32 (27.6%)	58 (24.4%)	.52
Year 2010	211 (21.3%)	35 (30.2%)	49 (20.6%)	.05 *

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

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

Table 2

Regression results for hospice versus home health care use among MCCC children (N=989)

Variables	Hospice Care		Home Health Care	
	RRR	95% CI	RRR	95% CI
Independent Variables				
Age				
6 to 14 years	0.75	(0.43–1.30)	0.57	(0.37–0.88) *
15 to 20 years	0.74	(0.42–1.33)	0.48	(0.30–0.75) **
Female	1.24	(0.82–1.87)	1.36	(0.98–1.89)
Race				
Caucasian	1.16	(0.61–2.22)	0.92	(0.52–1.63)
Other	0.58	(0.27–1.22)	0.72	(0.40–1.29)
Hispanic	0.68	(0.41–1.12)	0.79	(0.53–1.16)
Usual Source of Care	1.47	(0.84–2.59)	4.47	(2.49–8.02) ***
Hospice Accessibility	1.52	(0.83–2.79)	0.71	(0.46–1.11)
Pediatric Hospital Accessibility	0.69	(0.44–1.08)	1.53	(1.06–2.21) *
Neighborhood Socio-Economic	2.63	(0.61–11.34)	2.23	(0.70–7.08)
Public Policy Support	1.55	(0.79–3.05)	0.64	(0.33–1.25)
Case Management	1.11	(0.65–1.90)	1.13	(0.76–1.69)
Diagnosis				
Cancer	1.16	(0.69–1.95)	1.13	(0.77–1.69)
Congenital Anomalies	0.86	(0.52–1.42)	1.41	(0.97–2.03)
Cardiovascular Conditions	0.43	(0.27–0.68) ***	1.27	(0.88–1.83)
Intellectual Disabilities	0.99	(0.52–1.89)	0.75	(0.46–1.24)
Cerebral Palsy	0.99	(0.54–1.85)	1.50	(0.94–2.40)
Epilepsy	0.83	(0.51–1.46)	1.25	(0.84–1.86)
Disability Status	0.58	(0.29–1.16)	1.16	(0.61–2.21)
Psychological Status	0.99	(0.62–1.57)	1.19	(0.85–1.68)
Functional Status	2.47	(1.19–5.13) *	7.90	(3.30–18.91) ***
Year 2008	1.09	(0.58–2.05)	0.73	(0.46–1.15)
Year 2009	1.23	(0.65–2.30)	0.88	(0.55–1.41)
Year 2010	1.68	(0.88–3.21)	0.98	(0.59–1.63)

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

Note: RRR, relative risk ratio, CI, Confidence Intervals.