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Children with intellectual disability and hospice utilization

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Abstract

Over 42,000 children die each year in the United States, including those with intellectual disability (ID). Survival is often reduced when children with intellectual disability also suffer from significant motor dysfunction, progressive congenital conditions, and comorbidities. Yet, little is known about hospice care for children with intellectual disability. The purpose of this study was to explore the relationship between intellectual disability and hospice utilization. Additionally, we explored whether intellectual disability combined with motor dysfunction, progressive congenital conditions, and comorbidities influenced pediatric hospice utilization. Using a retrospective cohort design and data from the 2009 to 2010 California Medicaid claims files, we conducted a multivariate analysis of hospice utilization. This study shows that intellectual disability was negatively related to hospice enrollment and length of stay. We also found that when children had both intellectual disability and comorbidities, there was a positive association with enrolling in hospice care. A number of clinical implications can be drawn from the study findings that hospice and palliative care nurses use to improve their clinical practice of caring for children with ID and their families at end of life.

Keywords

intellectual disability; hospice care; Medicaid; pediatric hospice utilization; hospice enrollment; hospice length of stay

Over 42,000 children die each year in the United States, including children with intellectual disability (ID).¹ The American Association on Intellectual and Developmental Disabilities defines intellectual disability as a limitation in intellectual functioning (e.g., reasoning, learning, problem solving) and adaptive behaviors (e.g., understanding numbers, money,

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time), which is categorized as mild, moderate, severe, and profound.² It is common for this disability to originate before the age of 18.² Children with ID have an increased risk of early death compared to the general population.³ In California, for example, children with severe or profound ID have a mortality rate of 3.8 per 1000 deaths, compared to 0.31 per 1000 among all children.^{4,5} Survival is further reduced when children with ID suffer from significant motor dysfunction (e.g., epilepsy), progressive congenital conditions (e.g., Down Syndrome), and comorbidities.^{6–8}

At end of life, children with ID often receive care in their home or group homes with limited hospice care utilization.^{9,10} Pediatric hospice is a multidisciplinary team approach to care for children with a 6-month-to-live prognosis that focuses on managing pain and symptoms and ensuring quality of end of life for the child and their family.^{11,12} Hospice has been shown to significantly improve the end-of-life care in children, but with slow adaptation into the pediatric health arena.^{13–15} Pediatric hospice care can provide a layer of support for families as the child progresses in the end-of-life trajectory. However, many children with ID reside in group homes that focus on skills training, residential services, and adjunctive therapy with less priority historically given to end-of-life care services such as hospice. In addition, the clinicians caring for children with ID often lack knowledge about hospice care.^{16–19} Thus, children with ID are generally under-referred to hospice care.¹⁷ Although, most parents of children with ID desire an end-of-life experience free of suffering that promotes quality of life,²⁰ these children rarely receive the benefit of hospice care at end of life.

Despite the importance of hospice for children with ID, little is known about this end-of-life care for these children. What we know from the few adult and pediatric studies is that individuals with ID are typically marginalized at end of life. Utilization of hospice care (i.e., enrollment, length of stay) is often delayed or diminished because of communication challenges between ID children and clinicians. The inability of children with ID to effectively communicate health care intentions may hinder enrollment into hospice care.^{17,19,21–23} As an example, children with ID may have difficulties participating in and communicating their wishes for hospice care through advance care planning because of their disabilities. Furthermore, it is common for children with ID to have family members or other care providers serve as primary decision-makers with limited or no patient input, which can also impede utilization of hospice.²⁰ For children with ID, their disability status may play a role in accessing and using hospice care services; yet, no studies were found that explored the impact of ID status on pediatric hospice utilization.

Improving knowledge of hospice use for children with ID has significant clinical relevance. In a position statement, *Caring at the End of Life*, the American Association on Intellectual and Developmental Disabilities stated, “Evidence exists to indicate that people with intellectual and developmental disabilities are particularly at risk when caregivers do not have clear, consistent, and ethically sound guidelines” (para. 1),²⁴ regardless of age. Examining hospice use among children with ID may provide important insight into the complex needs of these children and enable hospice and palliative nurses and other practitioners to develop clinical practices that promote quality hospice care for children with ID.¹⁷ Therefore, the main objective of this study was to investigate the impact of ID on hospice utilization for children. This research addressed two specific questions: (1) what

effect does ID have on the utilization of pediatric hospice care services, and (2) does ID combine with motor dysfunction, progressive congenital conditions, and comorbidities to influence pediatric hospice utilization.

Methods

Design and Sample

The study was a retrospective, cohort design to examine the effect of ID on hospice utilization, while controlling for child and family characteristics. Children were included in the study if they were between the ages of 0 and 20 years, 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 based on the *International Classification of Diseases, 9th revision* (ICD-9) code as recommended by Feudtner and colleagues.²⁵ Children were excluded from the study if they had missing entries, were not California residents, or participated in Medicaid-managed care plans. The sample consisted of 1,012 children after applying inclusion and exclusion criteria. This study was approved by the Institutional Review Board at the University of Tennessee, Knoxville.

Data Sources

The data source for the study was the 2009 and 2010 California Medicaid claims files (Medicaid Analytic Extract [MAX]). The Medicaid Person Summary file were used for enrollment and demographic information and the MAX Other Services files provided procedure codes for hospice care services and *ICD-9* diagnosis codes. The MAX Other Services files contain records for a variety of Medicaid services such as physician services, lab/X-ray, clinic services, home health, hospice and outpatient hospital claims. Medicaid claims data were used because it is one of the few data sources that includes pediatric hospice utilization information. California was selected for this study because it has the largest population of children enrolled in Medicaid of any state.²⁶

Measures

Dependent variables—Two dependent variables of pediatric hospice utilization were created: *hospice enrollment* and *hospice length of stay*. Hospice enrollment was defined as whether or not a child used any hospice care in their last calendar year of life based on hospice procedure codes in the MAX Other Services files. The same files were used to create the hospice length of stay variable, which was operationalized as a daily count of hospice care encounters in the last year of life.

Independent variables—The independent variable of interest was *intellectual disability*. Using the diagnosis codes in the MAX Other Service files, children with *ICD-9* codes of 318.0–319.0 were defined as having moderate to profound ID.²⁵ *Motor dysfunction* was operationalized as whether or not children had a diagnosis of epilepsy. Children with chromosomal and other congenital anomalies were regarded as having progressive *congenital anomalies*. *Comorbidities* were classified as having two or more complex chronic

conditions. Interactions terms were created between intellectual disability and motor dysfunction, congenital anomalies, and comorbidities.

Covariates—Potential confounding variables with pediatric hospice utilization included *age, gender, race, ethnicity, case management, and co-insurance*.²⁷ Age was classified as less than 1 year to 5 years of age, 6 to 14 years, and 15 to 20 years. Gender was defined as male or female. Children's race was categorized as Caucasian or non-Caucasian and ethnicity was Hispanic or non-Hispanic. Case management was categorized as having an assigned Medicaid case manager or not. Whether or not children had additional private health insurance was a measure of co-insurance.

Statistical Analysis

Descriptive statistics including means, percentages, minimums, and maximums were calculated for all study variables, using pooled cross-sectional data from the years 2009 and 2010. Separate analyses were conducted for hospice enrollment and hospice length of stay. A logistic regression was used to estimate the association between ID and hospice enrollment because the measure of hospice enrollment was binary.²⁸ The logistic regression analysis results are reported as adjusted odds ratios (OR), which is interpreted as an OR less than 1 indicates that the chance of the hospice enrollment is low or negative; whereas an OR more than 1 indicates that the chance of hospice enrollment is high or positive. A negative binomial model, conditional on any hospice enrollment, was used to explore the relationship between ID and hospice length of stay. This analytic model was well suited for estimation based on count data such as the number of hospice days and 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.²⁸ Negative binomial results were reported as adjusted incidence rate ratios (IRR) and are interpreted as an IRR less than 1 indicates a decrease in the number of days enrolled in hospice care; whereas an IRR more than 1 indicates an increase in the number of hospice days. Statistical analyses were performed using Stata 11.0 (StataCorp LP, College Station, TX).

Results

Summary statistics are presented in Table 1. Overall, 12% of children in this study enrolled in hospice care with an average length of stay of 3 days. Almost 20% of children had an ID. Among children with ID in the last year of life, 10% enrolled in hospice with an average enrollment of less than a day (data not shown). Over 15% of the children in the sample had a motor dysfunction, while 17% had progressive congenital anomalies. Almost half of the children (47.1%) had multiple complex chronic conditions. The most common age group was less than 1 year to 5 years (42.9%) and females were 30% of the sample. Children were most frequently non-Caucasian (82.51%) and over a third were Hispanic (36.56%). Approximately 30% had a Medicaid case manager. Fourteen percent of the children had coinsurance in the form of private insurance.

The regression results estimating the association between ID and hospice enrollment are displayed in Table 2. Intellectual disability was significantly associated with hospice enrollment. The odds of enrolling in hospice care were lower for children with ID

(OR=0.12, $p<0.01$) compare to those without ID. However, when children had both ID and comorbidities, they were almost 8 times more likely to enroll in hospice (OR=7.83, $p<0.05$). Co-insurance was negatively associated with hospice enrollment (OR=0.30, $p<0.01$). No other factors were related to hospice enrollment.

The results of the negative binomial regression analysis, estimating the association between children with ID and hospice length of stay, are also shown in Table 2. A decrease in days enrolled in hospice care was observed for children with ID (IRR=0.06, $P<0.05$). Similarly, children with motor dysfunction were related a decline in hospice length of stay (IRR=0.22, $p<0.01$). Children with comorbidities, however, were associated with an increase in hospice length of stay (IRR=2.18, $p<0.05$). No interactions between ID and motor dysfunction, congenital anomalies, and comorbidities were statistically associated with days in hospice care. The covariates of age 15 to 20 years (IRR=0.44, $p<0.05$) and case management (IRR=3.40, $p<0.01$) were significantly associated with hospice length of stay; while controlling for other covariates had no significant relationship with length of stay.

Discussion

The goal of the study was to examine the relationship between children with ID and hospice utilization. There was a significant portion of children at end of life who had an ID. More than 17% of pediatric decedents in this sample had moderate to profound ID. In addition, ID was a significant predictor of hospice utilization. We found that children with ID were less likely to enroll in hospice care. This finding was consistent with the prior studies of individuals with ID and suggests that lack of enrollment in hospice care may be common among those with ID regardless of age.^{17,22} Children with ID often have family members or other care providers serving as primary decision makers because of cognitive limitations. It is possible that ID children may not have the ability to participate in their own care.¹⁸ Emerging evidence suggests that persons with ID exhibit a poor understanding of the concept of death and know very little about advance care planning, but they have a great fear of death.²⁹ Although our data did allow for exploration into the capacity for self-determination among children with ID, future research examining the ability to understand death and participate in advance care planning is warranted.

Even though ID only was negatively related to hospice enrollment, ID combined with comorbidities changed the outcome. Children with both ID and multiple complex chronic conditions were significantly more likely to enroll in hospice care. Our finding is consistent with the adult ID literature that reported comorbidities increase the risk of mortality among people with ID.^{6,8} Subsequently, the severity of their health condition may facilitate hospice enrollment. Children with ID often suffer disproportionately high rates of complex chronic conditions including coronary heart disease, respiratory disease, and cancer.^{6,30} Pediatric hospice care may be an important option for these children and their families as they seek to manage pain and symptoms associated with ID and comorbidities at end of life.

The study also revealed that ID predicted hospice length of stay. In this study, ID was associated with a decrease in days enrolled in hospice care. Additionally, when we examined length of stay among ID children only, we found that it dropped from an average of 3 days

for the whole sample to less than a day for children with ID. Utilizing hospice care for a day minimizes the ability of hospice and palliative care nurses to deliver effective end-of-life care. Hospice care for a patient enrolled and actively dying, as in the case of these children, requires significant time and resources from staff to conduct the initial assessment, consult with the hospice team, assess medications, and provide hospice services. Enrollment in hospice for a day suggests that there is no time for nurses to provide effective pain and symptom management or engage social work services or pastoral care. Hospice care is condensed into 24 hours for these children, whereas adults are commonly enrolled in hospice for several months, which enables more comprehensive care.³¹ The literature has shown that a family's overall satisfaction with hospice care is directly related to number of days enrolled in end-of-life services. Families experience a higher rate of perceived unmet needs with fewer days in hospice.³² However, the nature of our claims data leaves some unanswered questions about whether families are satisfied with only one day of hospice care. Thus, future research might explore family satisfaction with hospice care for children with ID.

This study explored covariates related to hospice utilization. Interestingly, we found that children with a Medicaid case manager had a higher number of days enrolled in hospice care. This may reflect the important role that a case manager can play in providing resources, health care navigation, and care coordination at end of life for at-risk pediatric patients such as children with ID. The findings suggest that a coordinated approach to end-of-life care among members of a child's healthcare team may be required for a transition to hospice care.³³ Additional research is needed to examine the role of case management in hospice enrollment and timing of enrollment among children with ID.

There were several study limitations to report. The findings on this study are generalizable only to the pediatric Medicaid population in California. Although California has the largest number of pediatric Medicaid beneficiaries and is often the policy leader in end-of-life care, the result might differ among children who reside in other states or countries. In addition, our data had a relatively high percentage of non-Caucasian children, which would be anticipated in a Medicaid population, but not in the general population. Thus, selection bias may be present in the study. Finally, our data included the last calendar year of life for children. It did not include a comprehensive claims history for children in the study. As a result, the hospice length of stay may have been truncated or under-reported for some children in this study.

A number of clinical implications can be drawn from the findings of the study. First, understanding the lack of pediatric hospice enrollment and length of stay among a children with ID and their families provides hospice and palliative care nurses with an important educational opportunity. Nurses can use this information to engage the hospice team, children, and families in education about the caring for children with ID. Children with ID and their families might benefit from a conversation about advance care planning and how hospice fits into the needs of the child and family.

Second, hospice and palliative care nurses might use this study information to develop quality improvement projects within their organizations. As hospices and palliative care

providers incur increased financial pressures to measure quality of care and to actively engage in quality improvement projects, examining the ability of the hospice to provide care for children with ID may be an opportunity for quality improvement. Examples of quality improvement projects include establishing special protocols for children with diminished cognitive abilities, creating an in-service educational series on ID in partnership with special education instructors, or developing educational materials for neonatologists and/or pediatric neurologists about pediatric hospice care for their ID patients.

Finally, hospice and palliative care nurses who care for children with ID have special opportunity to share their knowledge about caring for these underserved children and their families. Much is unknown about providing end-of-life care for children with ID, so clinical information from nurses is critical. Nurses can contribute information through Hospice & Palliative Nurses Association (HPNA) special interest group blogs, presentations at hospice and palliative care clinical conferences, or articles in clinical journals. Sharing best practices and methods to overcome challenges informs nursing practice. Clinical information on caring for children with ID ultimately improves the quality of care delivered.

In summary, as one of the first studies to explore the impact of ID on pediatric hospice utilization, this research contributes to the knowledge-base of end-of-life care for a special group of underserved children. Our study demonstrated that children with ID have limited use of hospice care at end of life. The results suggest that ID negatively affected pediatric hospice enrollment and length of stay. With this knowledge, hospice and palliative care nurses can improve their clinical practice of caring for children with ID and their families at end of life.

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Table 1

Descriptive Statistics of Study Variables (N=1,012)

Variables	n	% or Mean/SD
Hospice Enrollment	1012	12.15%
Hospice Length of Stay	1012	3.09 days(19.0)
Intellectual Disability	173	17.09%
Motor Dysfunction	159	15.71%
Congenital Anomalies	177	17.49%
Comorbidities	477	47.13%
Age		
< 1 year to 5 years	434	42.89%
6 to 14 years	279	27.57%
15 to 20 years	299	29.55%
Female	464	45.85%
Race		
Caucasian	177	17.49%
Non-Caucasian	825	82.51%
Hispanic	370	36.56%
Case Management	296	29.25%
Co-insurance	142	14.03%

Note: SD, standard deviation

Table 2

Regression Analyses for Hospice Utilization (N=1,012)

	Hospice Enrollment		Hospice Length of Stay	
	OR	95%CI	IRR	95% CI
Independent Variables				
Intellectual Disability (ID)	0.12 **	0.026–0.592	0.06 *	0.006–0.660
Motor Dysfunction	0.88	0.467–1.669	0.22 **	0.073–0.647
Congenital Anomalies	1.30	0.740–2.280	1.33	0.622–2.866
Comorbidities	1.02	0.654–1.576	2.18 *	1.102–4.299
ID × Motor Dysfunction	2.67	0.746–9.545	3.03	0.505–18.229
ID × Congenital Anomalies	1.21	0.327–4.462	1.67	0.321–8.680
ID × Comorbidities	7.83 *	1.468–41.711	0.94	0.064–13.925
Covariates				
Age				
< 1 to 5 years	(ref)			
6 to 14 years	1.50	0.926–2.414	0.87	0.459–1.651
15 to 20 years	0.91	0.545–1.530	0.44 *	0.224–0.882
Female	0.80	0.538–1.184	0.77	0.422–1.406
Caucasian	1.25	0.714–2.174	1.32	0.633–2.749
Hispanic	0.78	0.503–1.216	1.39	0.791–2.450
Case Management	0.93	0.565–1.528	3.40 **	1.423–8.122
Co-insurance	0.30 **	0.127–0.717	0.99	0.270–3.619

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

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