End-of-Life Healthcare Service Needs Among Children With Neurological Conditions: A Latent Class Analysis

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ABSTRACT

BACKGROUND: At the end of life, children with neurological conditions have complex healthcare needs that can be met by providing care of their life-limiting conditions concurrently with hospice care (ie, concurrent care). Given the limited literature on concurrent care for children with neurologic conditions, this investigation aimed to identify patterns of nonhospice, healthcare service needs and to assess characteristics of children within each group. **METHODS:** A nationally representative sample children with neurological conditions enrolled in concurrent hospice care was used. Latent class analysis and descriptive statistics were calculated to identify patterns of healthcare needs and characteristics of children within the groups. A subgroup analysis of infants was conducted. **RESULTS:** Among the 1601 children, the most common types of services were inpatient hospitals, durable medical equipment, and home health. Two classes of service needs were identified: moderate intensity (58%) and high intensity (42%). Children in the moderate-intensity group were predominantly between 1 and 5 years old, male, White, and non-Hispanic. The most common neurological condition was central nervous system degeneration. They also had significant comorbidities, mental/behavioral health conditions, and technology dependence. They commonly resided in urban areas in the South. Children in the high-intensity group had a wide range of neurological conditions and high acuity. The subgroup analysis of infants indicated a different neurological profile. **CONCLUSIONS:** Two distinct classes of nonhospice, healthcare service needs emerged among children with neurological conditions at the end of life. The groups had unique demographic profiles.

Keywords: concurrent hospice care, healthcare services, infants, latent class analysis, neurological conditions, nursing, pediatric hospice care, pediatrics

Children with neurological conditions at the end of life have unique and complex care needs. Many pediatric patients with life-limiting conditions such as brain/spinal cord malformation, central nervous system (CNS) disease, and infantile cerebral palsy have experienced poor health their entire, short lives. They often experience a wide range of nervous system symptoms including developmental delays, lack of coordination, changes in mood, seizures, muscle wasting, swallowing difficulties, and slurred speech. Consequently, their healthcare service needs can be significant, especially at the end of life. The enactment of the 2010 Affordable Care Act (Section 2302) allows children and their families to

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continue healthcare services for the child's life-limiting condition while enrolled in hospice care. Concurrent hospice care changed the hospice eligibility rules for children in Medicaid or Children's Health Insurance Program.[1]

Although there is increasing evidence about pediatric concurrent hospice care,[2–4] the healthcare service needs of children with neurological conditions during concurrent care have not received sufficient attention. In a series of case reports, Miller et al[5] identified the healthcare service needs of pediatric patients in concurrent hospice care with degenerative neurologic disorders, progressive inflammatory polyneuropathy, and Huntington disease with intractable seizure. They found special feedings, medications, ventilators, and private duty nursing were the most common healthcare services used among these children. No other studies were identified that included this population at the end of life.

Given the limited literature on healthcare service needs in concurrent hospice care for children with neurological conditions, the current investigation had 2 aims. The first aim was to apply latent class analysis (LCA) to identify patterns of nonhospice, healthcare service needs among children with neurological conditions. The second aim of the study was to assess the characteristics of latent class membership.

Methods

Data for this retrospective cohort designed study were from the Centers for Medicare & Medicaid Services (CMS) Medicaid files, 2011–2013. The Medicaid files are national claims data collected annually by CMS. Although the intent of the claims data is to document payment to healthcare providers for services rendered to Medicaid beneficiaries, CMS provides data files for healthcare research upon approval of study protocols, data management plans, and data use agreement.[6] Data are from all 50 states and the District of Columbia. For each Medicaid beneficiary, person-level research files are created by CMS and include Personal Summary (eg, demographics), Inpatient (eg, hospital admissions and procedures), Prescription Drugs (eg, medications and dates), and Other Services (eg, hospice, durable medical equipment, dental) records.[7] Medicaid data are one of the only national sources of information on children enrolled in hospice care.

The sampling frame for this study was limited to children in hospice care, which was 21 383 children in the Medicaid data. The sample was restricted to children who received pediatric concurrent hospice care, which is defined as the receipt of hospice and nonhospice, healthcare services simultaneously during hospice enrollment. Pediatric concurrent hospice care is federally mandated for all state Medicaid programs by the Affordable Care Act, Section 2302.[1] Children with life-limiting, neurological conditions

(ie, brain/spinal cord malformation, mental retardation disability, CNS disease, infantile cerebral palsy, epilepsy, other neurological conditions [ie, occlusion of cerebral arteries, muscular dystrophies, myopathies, movement disease]) as classified by Feudtner et al[8] were also included. Because pediatric concurrent hospice care is only available for children younger than 21 years, children older than 21 years were excluded. In addition, if dates of birth or death were missing, children were excluded from the study. The final sample was 1601 children with neurological conditions, who received pediatric concurrent hospice care. The institutional review board of the University of Tennessee, Knoxville reviewed and approved the study.

Measures
Healthcare Service Needs
Several steps were used to create the measures of nonhospice, healthcare service needs from the Medicaid data. First, nonhospice healthcare services were identified in the Inpatient, Other Services, and Prescriptions records. Using a date algorithm, the service dates were matched with hospice care dates and retained.[9,10] Next, the healthcare service needs were coded using CMS-assigned service labels. Twenty labels were used including inpatient hospital, durable health equipment, home health, medications, laboratory tests and x-rays, other services, targeted case management, physician services, outpatient hospital, personal care, private duty nursing, transportation, rehabilitation, physical therapy/occupational therapy/speech therapy, clinic, other practitioners, psychiatric services, dental services, residential care, and nurse practitioner services. Individual measures were created for each category and dichotomized as "yes" or "no."

Demographics
A set of demographic variables was created for this study. Age group was operationalized as younger than 1 year, 1 to 5 years, 6 to 14 years, and 15 to 20 years. Sex was dichotomized as female or male. White, Black, and other races were the categories for race, whereas ethnicity was either Hispanic or non-Hispanic. Comorbidities were defined as the presence of multiple complex chronic conditions.[11] Mental/behavioral health conditions and technology dependence were dichotomized variables.[8,12] Measures of the child's residence were rural/urban and region (Midwest, Northeast, South, and West).[13]

Data Analysis
The primary goal of this study was to apply the LCA to identify unobserved latent subgroups of children with neurological conditions in concurrent hospice care with respect to their nonhospice healthcare

service needs.[14] The second goal was to assess the demographic characteristics of latent class membership. A series of LCA models with an increasing number of latent classes were created from the healthcare service needs and used to determine the optimal number of latent classes.

To approximate the optimal number of latent classes, the number of classes estimated was increased incrementally 1 class at a time until LCA goodness-of-fit measures indicated that model testing should cease. Overall fit of each model was assessed using several statistical measures including the Lo-Mendell-Rubin likelihood ratio (detects the correct number of classes), log likelihood (detects the correct number of classes), Akaike information criterion (evaluates the quality of a model), Bayesian information criterion (evaluates the quality of a model), and entropy values (identify the distinctness of classes).[15,16] Once the number of latent classes was identified, the prevalence rates of the latent classes and the conditional item probabilities of the individual healthcare service needs were calculated and values greater than 0.50 were used to define classes.[17] Children were classified into an appropriate latent class based on conditional probabilities. Descriptive statistics were calculated to describe the demographic characteristics within the latent classes (ie, frequencies). A subgroup analysis was performed among infants younger than 1 year with neurological conditions in concurrent hospice care to examine their unique demographic profile in the latent classes. All analyses were conducted with Stata, version 15.[18]

Results

Table 1, Supplemental Digital Content 1 (available at http://links.lww.com/JNN/A358) displays the healthcare service needs of children with neurological conditions in pediatric concurrent hospice care. The 1601 children in the study generated approximately 370 000 non-hospice, healthcare service claims while enrolled in hospice. The most common types of service were inpatient hospital (eg, enteral infusions, parenteral infusions, mechanical ventilation, transfusions), followed by durable medical equipment (eg, enteral feeding supplies, oxygen equipment, suctions/pumps), home health (eg, nursing, therapeutic exercise), and targeted case management. The least common service needs were residential care, dental care, and nurse practitioner care.

Model fit indices for the different LCA models are shown in Table 2, Supplemental Digital Content 2 (available at http://links.lww.com/JNN/A359). The 2-class model was considered optimal because the data fit better than the 1- or 3-class models. As the number of classes increased, the Akaike information criterion and Bayesian information criterion decreased at 2 classes, which indicated improved model fit.[19] In addition, the 2-class model had the highest entropy value, which also suggested best model fit.[20]

For the 2-class model, conditional item probabilities are presented in Table 3, Supplemental Digital Content 3 (available at http://links.lww.com/JNN/A360). Fifty-eight percent of the sample was classified into class 1; and 42%, into class 2. Class 1 was defined as "moderate intensity" with conditional probabilities greater than 0.50 for use of physician services (0.502) and medications (0.992). Class 2 was defined as "high intensity" because the conditional probabilities were very high in 6 categories including inpatient hospital (0.582), physicians (0.968), outpatient hospital (0.866), laboratory tests and x-ray (0.940), medications (0.999), and durable medical equipment (0.834). Figure 1 displays the conditional item probabilities by class.

FIGURE 1 **Conditional item probabilities of healthcare service needs by class.**
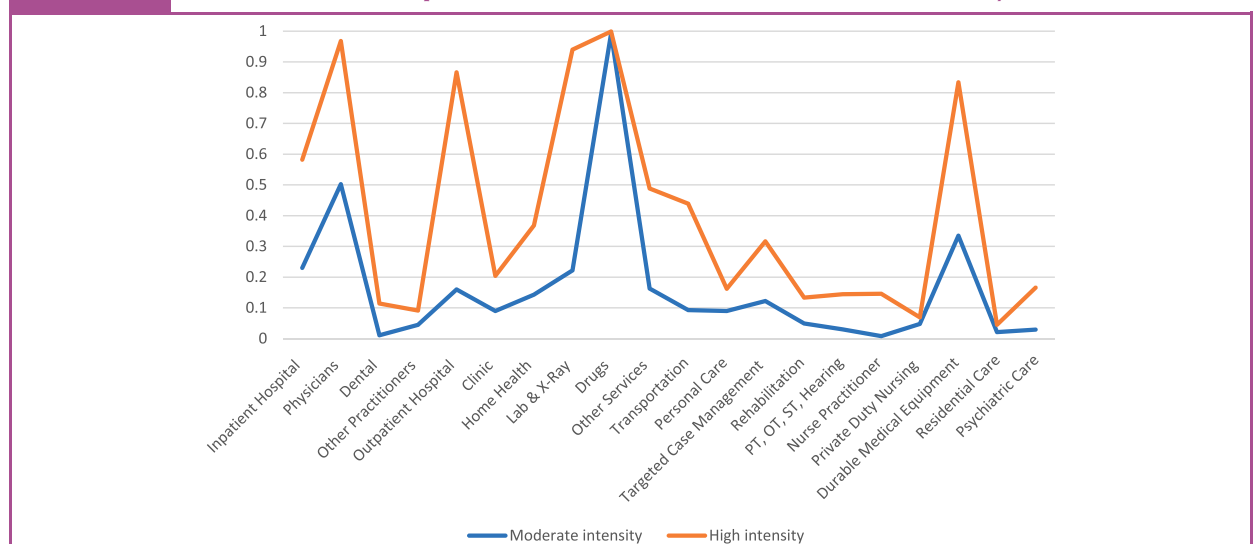
Variables	All Children	Class 1 Moderate Intensity n = 933	Class 2 High Intensity n = 668
TABLE 1. Characteristics of Children With Neurological Conditions in Concurrent Hospice Care Within the 2-Class Model (N = 1601)			
Age groups, y, %			
<1	14.1	10.9	18.4
1–5	37.7	36.1	40.0
6–14	31.9	33.2	30.0
15–20	16.3	19.8	11.6
Sex, %			
Female	46.6	47.5	45.4
Male	53.4	52.5	54.6
Race, %			
White	38.7	44.9	30.1
Black	13.9	14.8	12.6
Other races	47.4	40.3	57.3
Ethnicity, %			
Hispanic	22.4	22.1	22.9
Non-Hispanic	77.6	77.9	77.1
Neurological conditions,[a] %			
Brain and spinal cord malformations	41.19	39.8	43.1
Intellectual function	13.14	12.5	14.1
CNS degeneration and diseases	74.28	63.8	89.0
Infantile cerebral palsy	40.13	36.7	44.9
Epilepsy	31.89	27.9	37.5
Other disorders	20.44	19.1	22.4
Comorbidities, %	84.8	77.5	94.9
Mental/behavioral health conditions, %	67.6	62.0	75.5
Technology dependence, %	72.6	63.6	85.3
Rural/urban, %			
Urban	51.1	53.0	48.5
Rural	49.5	47.4	52.4
Region, %			
Midwest	20.3	21.0	19.3
Northeast	16.3	25.4	<10.0
South	41.7	34.0	52.5
West	21.7	19.6	24.6

Abbreviation: CNS, central nervous system.
[a]Neurological conditions are not mutually exclusive; <10.0 is noted for values less than 10% per Data Use Agreement.

The demographic characteristics of latent class membership are shown in Table 1. Children in class 1 were most frequently in the 1- to 5-year age group (36.1%), male (52.5%), White (44.9%), and non-Hispanic (77.9%). The most common neurological condition was CNS degeneration and diseases (63.8%), and the least common was intellectual dysfunction (12.5%). Most children in class 1 experienced comorbidities (77.5%), mental/behavioral health conditions (62.0%), and technology dependence (63.6%). These children frequently resided in urban areas (53.0%) in the South (34.0%). The group comprising class 2 was most often 1 to 5 years old (40.0%), male (54.6%), of other race (57.3%), and non-Hispanic (77.1%). Central nervous system degeneration and disease were the most common neurological condition (89.0%), and intellectual dysfunction was the least common (14.1%). The health of class 2 members was complicated by high comorbidities (94.9%), mental/behavioral health conditions (75.5%), and technology dependence (85.3%). Most children in class 2 resided in rural areas (52.4%) in the South (52.5%).

Analysis of infant characteristics within the 2-class model is listed in Table 4, Supplemental Digital Content 4 (available at http://links.lww.com/JNN/A361). Fifty-one percent of the infants were in class 1; and 48.8%, in class 2. Class 1 infants were characterized as predominately female (55.6%), White (44.4%), and non-Hispanic (100.0%). Brain and spinal cord malformations were the most common neurological condition (77.4%), followed by CNS degeneration and diseases (73.6%) and epilepsy (32.1%). Most of class 1 infants had comorbidities (77.8%) and technology dependence (66.7%). Infants in this class resided in urban areas (66.7%) in the Northeast (44.4%). Class 2 demographics highlighted a group of infants who were mostly male (62.5%), of other race (62.5%), and non-Hispanic (75.0%). The most common neurological conditions were brain and spinal cord malformations (78.43%), CNS degeneration and diseases (44.2%), and epilepsy (18.6%). All of the infants in this class had comorbidities and technology dependence. Their residence was frequently in urban areas (75.0%) in the South (50.0%).

Discussion

This study explored nonhospice, healthcare service needs among children with neurological conditions in concurrent hospice care. Two unobserved distinct latent classes were identified: moderate intensity (class 1) and high intensity (class 2). Both of these classes exhibited unique patterns of needs and demographic profiles from one another. The LCA presented a novel way of understanding groups of healthcare service needs among children with neurological

conditions that may inform tailored and targeted end-of-life care for different groups.

The group comprising the highest percentage of children with neurological conditions (58.3%) was class 1. Their healthcare service needs were more likely to be focused on physician services and medications. The high-intensity Class 2 group included 41.7% of the children in the sample. This group had high healthcare service needs, which ranged from inpatient hospital to outpatient hospital to auxiliary services such as laboratory tests, x-rays, medications, and durable medical equipment. The analysis revealed that children in this group were more likely to reside in rural areas, compared with class 1. This finding was unexpected. Children in rural areas at the end of life often have long distances to travel to healthcare services and, in many cases, traverse difficult terrain (eg, mountains). The challenges of transporting a child in a personal vehicle or with transportation services are complicated by very common symptoms such as nausea and vomiting, along with transporting equipment such as oxygen. For children with siblings, parents may have additional challenges of multiple children in the car. However, in this study, rural children in class 2 more often used healthcare services that normally would be located outside their community. Inpatient and outpatient services are often provided for children at the end of life at a children's hospital, which is almost exclusively located in urban areas. Research is needed to understand the experiences and perspectives of families in using high-intensity services while their child is in hospice care. Understanding the challenges and benefits of obtaining this type of care might inform the quality of delivery care for children.

The subgroup analysis among infants identified a different membership profile in the classes. Compared with the children in the study, infants had a different composition of neurological conditions. Whereas children in the overall sample primarily had CNS degeneration and diseases, infants frequently had brain and spinal cord malformation. This finding is consistent with the end-of-life literature examining the health of infants.[17] Although infants accounted for only 14% of the sample, it is important to note that they received high-intensity healthcare services. This is consistent with how palliative care is typically delivered in the neonatal intensive care unit: as a companion therapy to cure-oriented care.[21] How an infant may fare based on his/her condition at birth is hard to predict, and efforts are almost always initially focused on life-sustaining therapies. An infant's condition may improve for a period of days, or the infant may begin to languish for weeks or months, going on to develop complex chronic illnesses that require

escalating support. During this time, while curative care continues, the provision of concurrent palliative care may provide symptom management and other supportive care to the infant and the family until such time that a decision might be made to limit, or even to withdraw, life-sustaining therapies if the burdens of technological care begin to outweigh the benefits of treatment.[22,23] This breadth of findings suggests that programs and services be targeted by age and development to meet the particular demands of the condition and the particular needs of families.

Strengths and Limitations

There are several limitations to note. First, this study used Medicaid data. The findings are generalizable to this group of children and might be different among children in private insurance or Tricare in receipt of concurrent hospice care. Second, pooled cross-sectional data of claims during a 3-year period were used. Finally, the study used data from 2011 to 2013, which are aged. However, these data were the most current Medicaid data available, and they provided the first-ever and most currently available snapshot of the national healthcare services used by children with neurological conditions in concurrent hospice care.

Conclusion

As one of the first LCA studies of the healthcare service needs among children with neurological conditions during pediatric concurrent hospice care, this study provided evidence of unique groups of service needs. The results suggested that healthcare services cluster together in a unique fashion with distinct patterns of moderate and high intensities. In addition, the demographic composition of the classes differed widely, especially among a subgroup of infants. Taken together, the results can help clinicians, researchers, and policy makers advocate for services that meet the care demands and supports of children and families in a meaningful manner with targeted support.

Acknowledgment

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