Mental health and developmental disabilities in US children admitted in hospice care

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Abstract

Background: Of the 40,000 children who die annually in the United States (US), thousands are admitted to hospice care. Little is known about the mental health and developmental disabilities of these children.

Aims: To describe the mental health and developmental disabilities among children admitted in hospice care and compare across age groups.

Methods: The 2011 to 2013 US Medicaid files were used. The sample included 6,195 children with a mental health and/or developmental disability diagnosis. Comparisons were calculated using the Pearson chi-square.

Results: Mental health conditions including anxiety (31.0%), depression (33.1%), behavioral disorders (33.9%), and affective disorders (34.8%) were highest among children 15 to 20 years. Developmental delays were common in children under a year; while intellectual disabilities were highest in the 15 to 20 years age group.

Conclusions: Nurses have an important role in understanding the mental health and developmental disabilities of children admitted to hospice care.

Keywords

pediatric hospice care; end-of-life care; hospice care; pediatric mental health; developmental disabilities; Medicaid

Introduction

Of the 40,000 children who die annually in the United States (US), several thousand children are admitted to hospice care at end of life (Murphy et al, 2017). US pediatric hospice care offers children with a 6 month-to-live prognosis and their families supportive care to manage pain and symptoms, along with psychosocial supports (e.g., bereavement, respite). Although between 40% and 60% of children enter hospice with complicated, serious physical health problems, little is known about their mental health and developmental disabilities (Lindley

& Shaw, 2014). Mental health is the level of psychological well-being, and encompasses the emotions, behaviors and biology relating to a person's mental well-being (Soltis-Jarrett et al, 2017; World Health Organization, 2016). Mental health diagnoses range from single episode depression to more chronic conditions such as schizophrenia (National Alliance on Mental Illness, 2020). Developmental disabilities such as developmental delays, intellectual disabilities or attention deficit and hyperactivity disorder (ADHD) are long-term physical and mental conditions that impact learning and other activities of daily living (American Psychiatric Association, 2013).

Few studies have examined pediatric mental health and developmental disabilities at end of life, especially among children in hospice care. Kersun and Shemesh (2007) offered one of the first discussions on depression and anxiety in children at end of life. The authors challenged clinicians to recognize that symptoms and diagnosed disorders are different and might present differently at end of life. They also discussed the manifestations and treatment of symptoms associated with depression and anxiety. Lindley & Slayter (2018) examined the effect of physical health condition, mental/behavioral health problem, or a developmental disability on end-of-life quality for US foster care children from 2005 to 2015. They found that physical, mental, and developmental health were related to quality outcomes. More recently, a systematic review and meta-analysis examined the prevalence of anxiety and depression among children, adolescents, and young adults with life-limiting conditions (Barker et al, 2019). Of the 37 articles reviewed for the analysis, 19 reported on anxiety and 36 on depression. The meta-analysis revealed prevalence rates of 19% for anxiety and 14% for depression. In addition, nursing scholars empirically examined mental health or developmental disabilities among children admitted to US hospice care and found that more than half of children experienced depression even at their final hospice assessment (Lindley & Keim-Malpass, 2017). These researchers also reported that depression was more common among those with a single physical health condition, compared to multiple conditions. Although these findings are sparse, they suggest that children do experience significant mental health and developmental disabilities at end of life. The lack of comprehensive and generalizable evidence about the mental health and developmental disabilities of children in hospice care is a significant gap in our understanding of their end-of-life care.

This study contributes to the pediatric hospice literature in two important ways. First, using a large, nationally representative data set, the authors examined the frequency of mental health and developmental disabilities among US children admitted to hospice care. Second, this is the first study to compare the mental health and developmental disabilities of children in hospice care across age groups. This information is important for hospice and palliative care nurses and other clinicians caring for children to begin identifying populations at risk for mental health and developmental disabilities upon hospice admission. A better understanding of these children will promote a more comprehensive assessment of children entering hospice care. Therefore, the purpose of this study was to describe the mental health and developmental disability characteristics of children admitted to hospice care and compare characteristics across age groups.

Methods

Design & Data Sources

This study was a retrospective, non-experimental design. The main data source was the 2011 to 2013 US Medicaid data files. The information for the Medicaid files was collected by the US Centers for Medicare & Medicaid Services (CMS). They also prepared the files and ensured rigorous standards of data quality (Ruttner et a., 2015). Medicaid data are person-level, administrative claims information submitted electronically by all 50 states and the District of Columbia to CMS (Ruttner et al, 2015). Medicaid claims data were appropriate for this study because they are one of the few US data sources that includes hospice information on children in all states. Data from 2011 to 2013 were used because these were the most current data available. The other source of data was the publicly-available 2010 US Census data, which provided information on rural/urban. The Census data were manually linked to the Medicaid files by the Federal Information Processing Standards (FIPS) code.

Participants

The unit of analysis for the study was pediatric decedents. Children were defined as under 21 years. Participants were retained if they had a documented mental health and/or developmental disability diagnosis, which was based on primary and secondary ICD-9-CM codes from the Medicaid files as recommended by Garfield et al (2015). Admission to hospice between 1/1/2011 and 12/31/2013 was also an inclusion criteria. Children with either no service-level Medicaid claims or missing data were excluded. The final sample was 6,195 children over 3 years. This study was reviewed and approved by the University of Tennessee, Knoxville Institutional Review Board.

Measures

Four groups of variables were created for demographic, physical health, mental health, and developmental disability characteristics. Demographics included age, gender, race, ethnicity, and rural/urban. Age group categories were < 1 year, 1 to 5 years, 6 to 14 years, and 15 to 20 years. Gender was dichotomized as female and male. A child's race was operationalized as Caucasian or non-Caucasian, while ethnicity was Hispanic versus non-Hispanic. Rural/urban was defined using the Health Resources & Services Administration definition (Health Resources & Services Administration, 2018).

Physical health characteristics included complex chronic conditions, multiple complex chronic conditions, and technology dependence. Complex chronic condition was defined using the Feudtner et al (2014) definition and ICD-9-CM codes. Measures for each of the individual complex chronic conditions (i.e., neurologic/neuromuscular, cardiovascular, respiratory, gastrointestinal, metabolic, congenital/genetic, cancer) were also created. Multiple complex chronic conditions were defined as 2 or more complex chronic conditions (Lindley, 2017). Technology dependence was operationalized as whether a child was dependent on medical technology or device such as an insulin pump (Feudtner et al, 2005).

Mental health characteristics included anxiety, depression, behavioral disorders, affective disorders, and other mental health conditions (Garfield et al, 2015). Using ICD-9-CM

codes, the following measures were generated for diagnoses of anxiety (ICD-9-CM 300), depression (ICD-9-CM 300.4, 311, 296.2, 296.3), behavioral disorders (ICD-9-CM 308, 309, 312, 313), affective disorders (ICD-9-CM 296.1, 296.4-296.9, 291-293, 303-305), and other mental health conditions (dementias, persistent mental disorders, personality disorders, gender identity disorders, physiological malfunction, special symptoms, disorders due to brain damage, other psychiatric factors: ICD-9-CM 290, 294, 301, 302, 306, 307, 310, 316).

Several variables for developmental disabilities were created for this study. Following the examples of Garfield and colleagues (2015), the following ICD-9-CM codes were used to constructed the characteristics of developmental disabilities: developmental delays (ICD-9-CM 315), intellectual disabilities (ICD-9-CM 317-319), and other developmental disabilities (Autism, ADHD: ICD-9-CM 314, 295, 297-299).

Data Analysis

Using pooled cross-sectional data, the analysis included generating descriptive statistics on demographics, physical health, mental health, and developmental disabilities for all children in the sample. The children were stratified by age groups (< 1 year, 1-5 years, 6-14 years, 15-20 years) for the comparison analysis. The Pearson χ^2 test for differences in proportions was used to provide comparisons between the age groups. The results are presented in the form of univariate distributions. Because of small sample size in some categories, results with less than 10% or 10 observations were not reported, per our Medicaid Data Use Agreement. All analyses were conducted using Stata 15.0 software (StataCorp, 2017).

Results

The demographic characteristics of the children are displayed in Table 1. Among all children in the study, 45% were female and 42% non-Caucasian. Less than 20% of the children were Hispanic and more than a third resided in rural area. There were significant demographic differences across the age groups. Females (55.7%) and rural residence (42.5%) were most commonly in the 15 to 20 years age group. Children less than 1 year were most frequently non-Caucasian (56.5%) and Hispanic ethnicity (24.5%).

The physical health characteristics of children from the study are displayed in Table 2. More than half of the sample had a complex chronic condition (66.6%). Cardiovascular disease (31.1%) was the most frequent type of complex chronic condition and cancer was the least common (13.9%). More than 46% of children had multiple complex chronic conditions and 40% were technology dependent. Compared to other age groups, children less than 1 year had a significant higher proportion of complex chronic conditions (84.0%), multiple complex chronic conditions (59.9%), and technology dependence (48.0%).

Table 3 summarizes the mental health of children in the sample. The most common mental health condition was behavioral disorders (28.50%), followed by anxiety (16.4%), affective disorders (14.2%), depression (12.8%), and other (12.7%). Many of the mental health characteristics significantly differed by age groups. The age group 15 to 20 years predominately experienced anxiety (30.9%), depression (33.1%), and affective disorders (34.8%), compared to those 14 years and younger.

The variables that defined developmental disabilities are displayed in Table 4. Overall, almost half of the children in the study had a developmental delay (48.1%). Eleven percent of children had an intellectual disability and approximately a third had other developmental disabilities. There was variation in developmental disabilities across the age groups. The proportion of children under 1 year with a developmental delay was higher (79.3%) than the other age groups. Intellectual disabilities were most common (15.5%) in the 15 to 20 years group; while other developmental disabilities were highest (41.3%) in the 6 to 14 years age group.

Discussion

As one of the few studies of pediatric mental health and developmental disabilities at end of life, the goal of this study was to examine the frequency of these conditions in a sample of children admitted in hospice care. Understanding the mental health and developmental disabilities provides critical evidence on the health complexity among these children. The findings from the 2011 to 2013 data of 6,195 children showed that the US pediatric decedents were generally young, non-Hispanic and resided in urban areas.

The children in the study experienced a range of mental health and developmental disabilities. Anxiety, depression, behavioral disorders, affective disorders, and intellectual disabilities were highest among children 15 to 20 years; while developmental delays were common in children under a year. These findings are consistent with the general US pediatric population (Mahoney et al, 2017; Wagner, 2019). Although some of the mental health conditions do not manifest until a child is older (e.g., affective disorders), there are several possible explanations for the low prevalence of mental health conditions among young children. First, many of these conditions such as depression and autism are frequently assessed through verbal communication. Children are asked questions about their mood or attitudes which drive the diagnosis. However, very young children might lack the cognitive and verbal skills to express such difficulties (Shapiro, 2019).

Second, the parents might impact whether a child is diagnosed. For example, it is common for behavioral health problems among younger children to be identified by parents, who are their primary caregiver. However, it seems likely that the parents of these medically complex children might be more focused on physical health and less concerned about mental and behavioral health at end of life (Zimmerman et al., 2016). In addition, parents may lack the necessary knowledge to identify mental or behavioral health problems (Egger & Angold, 2006; Tully et al, 2019).

Finally, it is possible that hospice and other health care providers are not trained in mental health assessment and might fail to screen or identify mental health or developmental disabilities among their young patients (Irwin & Ferris, 2008). Many hospice nurses, physicians, and other clinicians are geriatric specialists and do not have expertise in identifying or assessing pediatric mental health and developmental conditions (Trachsel et al., 2016). Future research might explore the knowledge of and experience among parents and clinicians with assessment of pediatric mental health and developmental disabilities at end of life, particularly among predominately adult hospice providers.

Limitations

There are several notable limitations to the study. One of them is selection bias. The study sample included only those children who were admitted to Medicaid and hospice care at end of life, which limits the generalizability of findings. In addition, infants in the sample may be underrepresented, because life threatening diseases develop in this age very quickly and parents may not have had enough time to enroll them in the US Medicaid benefit. This process can take several months. Finally, because this study uses a Medicaid claims dataset, it has a limited number of contextual variables, such as family history, family characteristics, and psychological assessment results.

Implications

Despite these limitations, there are several key clinical implications for hospice and palliative care nurses. The study findings raise an interesting issue of treatment of diagnosed condition versus symptoms among children admitted to hospice care (Kersun & Shemesh, 2007). For example, anxiety or sadness may be troublesome without rising to the level of a diagnosable psychiatric disorders. In particular, anticipatory grief and sadness would be expected near end of life and would not necessarily constitute a disorder (Ashton & Ashton, 2000). Children's and their family's intense grief might be felt at the time of diagnosis or prognosis, which can be months or years before the actual death. Kerson & Shemesh (2007) contended mental health was complicated at end of life with clinicians often failing to recognize/treat a mental health, while clinicians who did treat mental health conditions frequently over-treated. Hospice and palliative care nurses caring for children might seek additional information on assessing mental health and developmental disabilities and resources for the provision of pediatric psychiatric services at end of life.

Conclusions

In summary, the prevalence of mental health and developmental disabilities was high for a group of children admitted to hospice care. In addition, they presented with a wide range of comorbid physical health conditions. The findings revealed significant age differences with younger children frequently being diagnosed with developmental delays and comorbid physical health problems, while older children and adolescents were more often diagnosed with mental health, intellectual disabilities and ADHD/autism. Hospice and palliative care nurses and members of the care team for these children have an important role in understanding and assessing for mental health problems and developmental disabilities.

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Table 1

Demographic characteristics by age groups (N = 6,195)

Variables	All Children	Age Groups				
		< 1 year, n = 319	1 to 5 years, n = 2,135	6 to 14 years, n = 2,202	15 to 20 years, n = 1,539	*P* value
Female	45.1%	52.4%	40.1%	41.6%	55.7%	<.001
Non-Caucasian	42.3%	56.5%	44.6%	39.2%	40.6%	<.001
Hispanic	18.1%	24.5%	16.7%	18.7%	18.1%	.007
Rural	37.1%	35.1%	31.6%	38.8%	42.5%	<.001

Table 2

Physical health characteristics by age groups (N = 6,195)

Variables	All Children	By Groups				P value
		< 1 year n = 319	1 to 5 years n = 2,135	6 to 14 years n = 2,202	15 to 20 years n = 1,539	
Complex Chronic Condition	66.6%	84.0%	65.4%	62.4%	70.5%	<.001
Neurologic/neuromuscular	29.8%	49.8%	33.2%	26.1%	26.3%	<.001
Cardiovascular	31.1%	54.2%	34.9%	25.2%	29.4%	<.001
Respiratory	23.3%	26.7%	23.0%	23.0%	23.5%	.517
Gastrointestinal	26.4%	35.1%	29.1%	23.0%	26.3%	<.001
Metabolic	16.4%	18.8%	16.0%	13.6%	20.5%	<.001
Congenital/Genetic	17.8%	38.9%	19.1%	14.9%	15.9%	<.001
Cancer	13.9%	NA	11.0%	14.7%	18.3%	<.001
Multiple Complex Chronic Conditions	46.7%	59.9%	49.2%	45.4%	42.2%	<.001
Technology Dependence	40.4%	48.0%	43.1%	41.6%	33.1%	<.001

Notes: NA = not able to report

Table 3

Mental health characteristics by age groups (N = 6,195)

Variables	All Children	By Groups				
		< 1 year n = 319	1 to 5 years n = 2,135	6 to 14 years n = 2,202	15 to 20 years n = 1,539	P value
Anxiety	16.4%	NA	NA	17.5%	30.9%	<.001
Depression	12.8%	NA	NA	12.0%	33.1%	<.001
Behavioral Disorders	28.5%	NA	16.3%	39.7%	33.9%	<.001
Affective Disorders	14.2%	NA	NA	10.9%	34.8%	<.001
Other Mental Health	12.7%	12.2%	11.8%	13.7%	12.9%	.319

Notes: NA = not able to report

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Table 4

Developmental disability characteristics by age groups (N = 6,195)

Variables	All Children	By Groups				
		< 1 year n = 319	1 to 5 years n = 2,135	6 to 14 years n = 2,202	15 to 20 years n = 1,539	P value
Developmental Delays	48.1%	79.3%	77.8%	38.0%	15.4%	<.001
Intellectual Disabilities	10.9%	NA	NA	12.1%	15.5%	<.001
Other Developmental Disabilities	26.6%	NA	15.2%	41.3%	26.7%	<.001

Notes: NA = not able to report