

Differences in Characteristics of Children with Cancer who Receive Standard versus Concurrent Hospice Care

Abstract

Background: The provision of Section 2302 of the 2010 Patient Protection and Affordable Care Act (ACA) allowed pediatric patients who are enrolled in Medicaid to receive hospice care concurrently with curative treatment (i.e., concurrent hospice care). Because it is a relatively new model of care and very little is known about the characteristics of children with cancer who receive it, the purpose of the current study was to compare demographic, health, and community characteristics of children who received standard hospice care versus concurrent hospice care.

Procedure: This study was a retrospective, comparison study with national Medicaid files provided by the Center for Medicare and Medicaid Services (CMS). The sample included 1,685 pediatric patients under the age of 20 who were diagnosed with cancer, were enrolled in hospice between 2011 and 2013, and received standard hospice care (n= 1,008) or concurrent hospice care (n = 655).

Results: Children of non-Caucasian race with multiple complex chronic conditions, mental/behavioral health problems technology dependence, and brain and orbital tumors, were more likely to be enrolled in concurrent care than in standard hospice care. The proportion of children enrolled in concurrent care versus standard hospice care was larger in rural areas, low-income communities, and in the Southern states.

Conclusions: The enhanced uptake of concurrent care by traditionally underserved populations is promising. Concurrent hospice care, which allows for continued medical treatment and hospice care, could enhance access to hospice within these populations by offering a more blended model of care.

Introduction

By recent estimates, more than 1,600 US children die from cancer every year.¹ Approximately 45% of these children enroll in hospice to receive end-of-life care.² The location of end-of-life care influences quality of life for both children and their families. Many parents prefer that their children receive end-of-life care in the inpatient setting because hospitals can provide state of the art pain management, which enables them to hope that their children will respond to treatment.³ However, hospitals have limited resources for providing support to parents: many hospitals do not have dedicated space and furniture for accommodating parents of hospitalized children,^{3,4} and they lack protocols for optimal communication between parents and medical personnel⁵⁻⁷ to ensure that children and their families are satisfied with decisions they make about their care.⁸ In contrast, parents who choose to enroll in hospice receive end-of-life care in their home settings. Hospices can provide a variety of services such as durable medical equipment, pain management, and psychosocial support to parents when the child dies.⁹⁻¹¹ As a result, parents who use hospice services report better quality of life, quicker adaption to normal social functioning, and less guilt than parents who chose in-hospital settings.¹²

Until recently, a barrier to hospice care utilization was that children had to forego curative treatments, therapies, and medications to enroll in hospice.² The provision of Section 2302 of the 2010 Patient Protection and Affordable Care Act (ACA) now allows pediatric patients under 21 years who are enrolled in Medicaid to receive hospice care concurrently with curative treatment (i.e., concurrent hospice care).¹³

Because concurrent hospice care is still a relatively new model of care at end of life, very little is known about characteristics of children with cancer who receive this type of care. What we do know is primarily focused on standard pediatric hospice care for children with cancer.

Previous work has shown that children with brain and solid tumors were more likely to use hospice care than those with leukemia or lymphoma.¹⁴ Previous studies also showed a lack of gender differences in hospice enrollment.^{14,15} One study found that Hispanic children with cancer are more likely to enroll in hospice than children of other ethnicities,¹⁵ while another showed that Caucasian children are the primary users of hospice services.¹⁴ The latter contradiction reflects a common problem that hospice studies are often conducted on samples that are limited by community or state boundaries.¹⁶

Understanding children with cancer who receive concurrent care and how they might differ from those in standard hospice care is clinically relevant. Concurrent care requires a more complex approach to care coordination, use of medication, and durable equipment than standard hospice care.⁶ It can also be more burdensome from an administrative perspective, because each caring facility and state may have its own guidelines for this type of care.¹⁷ The purpose of the current study was to compare demographic, health, and community characteristics of children who received standard hospice care versus concurrent hospice care.

Methods

Design and Data Sources

This study was a retrospective, comparison study with national Medicaid files provided by the Center for Medicare and Medicaid Services (CMS). The Medicaid dataset included person-level, administrative Medicare claims collected between 2011 and 2013 from 50 states and the District of Columbia,¹⁸ representing the most recent data available. Medicaid files were used because they are one of the few national data sources that includes pediatric hospice information. The Medicaid claims data includes information on demographics, health, and service use. Data quality is managed by CMS.¹⁹ For this study, Medicaid files were linked by

Federal Information Processing Standards (FIPS) codes with two other databases: (a) 2010 U.S. Census data, for information on community income; and (b) the database of rural areas defined as such by the Federal Office of Rural Health Policy (FORHP).²⁰ The study was approved by the Institutional Review Board of the University of Tennessee, Knoxville.

Sample

The sample included pediatric patients enrolled in hospice who met three inclusion criteria: (a) hospice admission between January 1, 2011 and December 31, 2013; (b) having a diagnosis of any type of cancer according to the coding system of the International Classification of Diseases, version 9 (ICD-9)²¹ with codes ranging from 140.0 to 239.9; and (c) age under 20 years, because patients who reach the age of 21 are not eligible for concurrent hospice care. Children with missing hospice records and dates of birth were excluded, resulting in a final sample of 1,685 children. Within the total sample, two groups were identified: 1,008 children (60.7%) who received standard hospice care; and 655 children (39.3%) who received concurrent care.

Measures

Three sets of measures were created for demographic, health, and community characteristics. Demographic measures included: age (0 to 5 years, 6 to 14 years, 15 to 20 years); gender (female and male); race (Caucasian and non-Caucasian); and ethnicity (Hispanic and non-Hispanic). Four measures of health were created. Multiple complex chronic conditions was defined as 2 or more conditions.⁹ Mental/behavioral disorders were based on the presence of a mental/behavioral health diagnosis.²² Whether children required complex medical technology or devices was the definition of technology dependence.²¹ Types of cancer were identified using ICD-9 codes: leukemia or lymphoma (ICD-9 codes: 200-202 and 204-8); brain and orbital

tumors (ICD-9 codes: 190-192); solid extracranial tumors, including cancers of the oropharynx (ICD-9 codes: 140-149); gastrointestinal cancers (ICD-9 codes: 150-159, 235); thoracic cancers (ICD-9 codes: 160-165); sarcomas (ICD-9 codes: 170-171); skin cancers (ICD-9 codes: 172-3, 176); breast cancers (ICD-9 codes: 174-5); endocrine and neuroendocrine cancers (ICD-9 codes: 193-4, 209, 237); and other (ICD-9 codes: 195, 199, 238, 239). Characteristics of communities were measured using rurality, income level, and geographic location. Rurality was identified using the rural-urban distinction of the FORHP. Community household income was identified using data from the US Census;²³ communities where median household income level was less than \$50,000 were classified as “low income” and otherwise as “high income”. Geographic region was classified using U.S. Census Bureau classification including Midwest, Northeast, South, and West.

Data Analyses

The primary aim of the study was to compare characteristics of children with cancer who received standard versus concurrent hospice care. Descriptive statistics were reported using frequencies and percentages. Differences between children receiving standard hospice care and concurrent care were computed using the test for differences in proportions (Pearson’s χ^2) with demographic, health, and community characteristics. Statistical analyses were performed using Stata 15.0.²⁴

Results

Demographic characteristics of children in standard hospice and concurrent hospice care are presented in Table 1. Forty percent of children were between the ages of 6 and 14 years. More than half were male (53.2%), non-Caucasian (56.3%), and non-Hispanic (79.8%). Demographic differences between children enrolled in standard and concurrent hospice care

were statistically significant only for race ($\chi^2 = 11.2$, $P = .001$); non-Caucasian children had higher rates of enrollment in concurrent hospice care than in standard hospice care (61.5% vs 56.3%, respectively).

Table 2 summarizes the health characteristics of children. Most children (73.1%) had multiple complex chronic conditions, and half had either mental/behavioral issues (51.0%) or depended on medical technology (51.6%). The most common cancer diagnosis was a solid extracranial tumor (58.3%), followed by brain/orbital tumors (25.4%), and leukemia/lymphoma (17.0%). Children with multiple complex chronic conditions were more likely to be enrolled in concurrent care (82.8%) than in standard hospice care (66.9%). Children with mental/behavioral health problems were more likely to be in concurrent care (55.9%) than in standard hospice care (47.9%), as were those with technology dependence (59.8% in concurrent care versus 46.2% in standard hospice). Children with brain and orbital tumors were more likely to receive concurrent hospice care (32.0%) than standard hospice care (19.8%). In contrast, children with solid extracranial tumors were more likely to receive standard hospice care (62.4%) over concurrent curative and hospice care (50.8%). For children with leukemia and lymphoma, there were no statistically significant differences in type of hospice use.

Community characteristics of children are presented in Table 3. Slightly less than half of all children resided either in rural areas (42.7%) or low-income communities (43.7%), and more than one third (37.51%) resided in the Southern region. All differences in community characteristics were statistically significant for children enrolled in standard and concurrent hospice care. Thus, the proportion of children enrolled in concurrent care versus standard hospice care was significantly larger in rural areas (47.0% and 39.9%, respectively) and in low-income communities (50.8% and 39.2%, respectively). Receipt of concurrent care was highly

disproportionate across the US regions. The proportion of children with cancer enrolled in concurrent hospice care in the South (48.04%) was three times larger than in the Northeast (14.4%) and West (16.6%).

Discussion

The goal of this study was to compare the characteristics of children who received standard versus concurrent hospice care in a national sample of Medicaid beneficiaries. Understanding the differences between children who received these two hospice care models provides critical information about health care utilization at end of life. The findings from this study revealed significant demographic, health, and community differences between those who used standard compared to concurrent hospice care.

In our national sample of children in hospice care, the findings demonstrated that children with cancer who were non-Caucasian and resided in rural, low-income areas of the South were more likely to receive concurrent care. While this study did not allow us to ascertain the reasons that some families chose concurrent care over standard hospice services, the enhanced uptake of concurrent care by traditionally underserved populations is promising. Previous work in adults has demonstrated underuse of hospice care among minority, low income, and rural populations. Some studies have shown that African American personal or cultural values can conflict with the hospice philosophy and be viewed as “giving up” on the patient.²⁵ Others have suggested that disparities in hospice use are a manifestation of structural inequalities in the health care system that underserves minorities living in poverty.²⁶ Therefore, concurrent hospice care, which allows for continued medical treatment and hospice care, might address conflicts in philosophy and improve access to care, which may ultimately reduce disparities in end-of-life care for these

children with cancer. Our findings suggest that concurrent care could enhance access to hospice within these populations by offering a more blended model of care.

Additionally, the study revealed that children who received concurrent care were significantly sicker at end of life than children in standard hospice care. More than 80% had multiple conditions, 56% had mental/behavioral health problems, and 60% were technology dependent. They also were more likely to have brain tumors compared to their peers in standard hospice. This study provided new evidence on the complexity of health among children with cancer in hospice care. Given the health profile of the children in this study, it would be expected that most children entered concurrent hospice care after serious illnesses requiring significant family support in the home as well as a history with multiple clinicians and services. These are exactly the children who stand to benefit most from concurrent care, which allows continued support for needed cancer treatments such as radiation and chemotherapy as well as other acute or chronic medical therapies.⁶ Additional research might continue to examine the services received by children with cancer during concurrent care to better understand the patterns of care received.

This study had several limitations to report. First, the study used administrative secondary data. These data are primarily collected to pay insurance claims for health care services and are not intended for national reporting of pediatric hospice care or end-of-life research. However, the Medicaid files are one of the very few data sources with pediatric hospice information from all states and the District of Columbia. Second, the study results are not generalizable beyond Medicaid beneficiaries. Although private health insurers might offer concurrent care, these results are limited to those enrolled in their state Medicaid plan. Third, the data for this study was limited to 2011 to 2013. While these data may be older, they represent the important early years

184 of ACA, Section 2302. Future research should explore more current Medicaid data available
185 through CMS as well as changes over time since passage of the ACA. Finally, the reporting of
186 specific cancer diagnoses was limited by our Data Use Agreement with CMS. Under this
187 agreement, we are not allowed to report any frequency or number under 10%. Thus, we were not
188 able to report on any rare cancer types.

189 Despite these limitations, the findings from the study have implications for clinical
190 practice among those who care for children with advanced cancer. Given the significant
191 differences between children who received standard versus concurrent hospice care, it is
192 important for oncology clinicians working with these children to be aware of the demographic,
193 health, and community profiles of children receiving this care. While concurrent care should be
194 offered to all patients who are approaching the end of life and have high needs for home care,
195 nurses and clinicians should keep in mind that provision of concurrent care may mitigate barriers
196 to hospice among underserved populations. When patients or family members have reservations
197 about using hospice, concurrent care remains an important part of the discussion of services
198 available, supporting dual goals of quality and length of life.

199 The results from the study also suggest opportunities for future research. Although
200 demographic and community characteristics were examined, additional research is needed to
201 understand concurrent hospice care among non-Caucasian, low-income, rural children with
202 cancer. Conducting well-designed mixed-methods studies of the experiences with and outcomes
203 of pediatric concurrent care among this underserved, understudied population might shed critical
204 insights into the role of concurrent care to meet the needs of these children and families, while
205 confronting actual and perceived structural racism present in end-of-life care.²⁵

206 In summary, this study compared the children with cancer who received standard and
207 concurrent hospice care in a national cohort of Medicaid beneficiaries. A comprehensive set of
208 measures was created from several databases including Medicaid data files. We sought to
209 compare demographic, health, and community characteristics between children who used
210 standard versus concurrent hospice care. The findings revealed significant differences between
211 standard and concurrent care recipients, which provides important insight into the profile of these
212 children. We found children with cancer who received concurrent hospice care were generally
213 non-Caucasian from low-income, rural communities in the South and they had markers of very
214 poor health, even relative to other children at end of life. This research has implications for
215 clinicians caring for children with cancer and researchers.

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