Differences in Characteristics of Dying Children Who Receive and Do Not Receive Palliative Care

WHAT’S KNOWN ON THIS SUBJECT: Pediatric palliative care (PC) can be beneficial to children with life-threatening conditions and their families by providing symptom management and control, sibling support, bereavement services, spiritual guidance, support in decision-making about limiting burdensome medical interventions, and advance directives.

WHAT THIS STUDY ADDS: Little is known about actual receipt of PC by dying children. This study compares characteristics of dying children by receipt of PC and highlights underserved patient groups who could be targeted to improve access.

abstract

OBJECTIVE: Comparing demographic and clinical characteristics associated with receipt of palliative care (PC) among children who died in children’s hospitals to those who did not receive PC and understanding the trends in PC use.

METHODS: This retrospective cohort study used the Pediatric Health Information System database. Children <18 years of age who died ≥5 days after admission to a Pediatric Health Information System hospital between January 1, 2001, and December 31, 2011 were included. Receipt of PC services was identified by the International Classification of Diseases, Ninth Revision code for PC. Diagnoses were grouped using major diagnostic codes. International Classification of Diseases codes and clinical transaction codes were used to evaluate all interventions.

RESULTS: This study evaluated 24,342 children. Overall, 4% had coding for PC services. This increased from 1% to 8% over the study years. Increasing age was associated with greater receipt of PC. Children with the PC code had fewer median days in the hospital (17 vs 21), received fewer invasive interventions, and fewer died in the ICU (60% vs 80%). Receipt of PC also varied by major diagnostic codes, with the highest proportion found among children with neurologic disease.

CONCLUSIONS: Most pediatric patients who died in a hospital did not have documented receipt of PC. Children receiving PC are different from those who do not in many ways, including receipt of fewer procedures. Receipt of PC has increased over time; however, it remains low, particularly among neonates and those with circulatory diseases. Pediatrics 2013;132:72–78
Approximately 55,000 children die every year in the United States, with approximately 80% dying in a hospital setting. Many hospital deaths are due to nonpreventable causes, including deaths of children with complex chronic conditions (CCCs). In 2001, Feudtner stated that approximately 15,000 children and young adults with CCCs die each year. Many of these children may benefit from palliative care (PC) services, which address symptom management and control, limiting burdensome medical interventions; help initiate discussions about advance directives and resuscitation orders; aid in discerning patient and family preferences; and provide sibling support, bereavement services, and spiritual guidance. Recent studies show a steady increase over the past 10 years in PC programs for adults and children. However, data from the National Hospice and Palliative Care Organization in 2010 showed that of the 1.58 million people who used hospice services, only 0.4% (6,320) were aged <24 years. Feudtner stated that on any given day, ~5,000 children are living within the last 6 months of their lives. The total number of children receiving PC services is unknown; however, it is estimated that 8,600 children would be candidates for PC services on any given day. To determine why many children who would likely benefit from PC are still not receiving these services, it is important to know who these children are and what differences exist between them and children who do receive PC. A recent study evaluating patient characteristics of children receiving PC services found the most common patient diagnoses include genetic/congenital disorders, neuromuscular disorders, and cancer diagnoses. Little is known about the characteristics of dying children not receiving PC. The main objectives of this study are to compare demographic and clinical characteristics associated with receipt of PC among children who have died in children’s hospitals to those who died but did not receive PC, and to understand the trends in the use of PC in U.S. children’s hospitals.

METHODS

Study Design and Data Source

This is a retrospective cohort study conducted using the Pediatric Health Information System (PHIS) database developed by the Children’s Hospital Association, a collaboration of >40 children’s hospitals across the United States. The PHIS database consists of partially deidentified administrative information including demographics, diagnosis, procedures, and charges. Most PHIS hospitals also submit level II data including charges for pharmacy, clinical services, imaging, laboratory, supply, and other information. This cohort includes PHIS hospitals with complete level II data only. All data are checked for reliability and validity before release. This study qualified for exemption from human subjects review by the University of Utah Institutional Review Board.

Patient Selection

We identified children <18 years of age who died ≥5 days after admission between January 1, 2001, and December 31, 2011. We chose 5 days to exclude children who died quickly after hospital admission, thus limiting time to access PC. Receipt of PC services was identified by the International Classification of Diseases, Ninth Revision (ICD-9) code for PC (V66.7).

Patient Variables

Patient variables include demographic information (child age, gender, and race), length of hospital stay (LOS), principal payer, and total patient charges. Patient charges provided to PHIS from each hospital were derived from the Centers for Medicare and Medicaid Services wage/price index for the hospital’s location and averaged per day. Patients were categorized by diagnosis using major diagnostic categories (MDC). MDCs group principal diagnoses into 1 of 25 groups based on major organ system or etiology of disease. Sixteen of these diagnostic groups had small patient numbers (<550) and were grouped into an “other” category for analysis (listed in Supplemental Appendix A). Four small groups with similar organ systems were combined (ie, HIV grouped with Infections; Digestive System grouped with Hepatobiliary System). Patients were identified as having CCCs as defined by Feudtner. CCCs were grouped as follows: cardiovascular, gastrointestinal, hematologic or immunologic, malignancy, metabolic, neuromuscular, other congenital or genetic defect, renal, and respiratory. To understand whether medical interventions differed among children who did or did not receive PC, we examined the following: medication use within the final 4 calendar days of life, procedures performed any time during admission, and location of death. Medications were abstracted using clinical transaction codes (CTC) for analgesics, sedatives, muscle relaxants, antiinfectives, and adrenergics (complete list in Supplemental Appendix B). Procedures are identified by CTC codes and ICD-9 codes. We identified the child’s location of death using the unit billing on the last hospital day. ICU location included NICUs and PICUs. The following ICD-9 codes and CTC codes were used to identify procedures: noninvasive mechanical ventilation (53.90), arterial catheterization (38.91, 89.61, 89.65, 00.68), central venous catheterization (89.62, 89.66, 38.93), hemodialysis (39.95, 38.95), intracranial pressure...
monitoring or extraventricular device (01.10, 01.28, 01.26), blood product transfusion (99.0, 99.04, 99.05, 99.06, 99.07, 99.09), or cardioversion (99.6, 99.60, 99.61, 99.62, 99.63, 99.69). PHIS-developed “flags” identified the following: mechanical ventilation, which includes ICD-9 codes 96.70, 96.71, or 96.72 and CTC codes 521166 or 521169; extracorporeal membrane oxygenation, which includes ICD-9 code 39.65 or CTC code 521181; total parenteral nutrition, which includes ICD-9 code 99.07, 99.09, 99.60, 99.61, 99.62, 99.63, 99.69). Statistical analysis was performed by nonparametric tests. Statistical significance was set at a $P$ value of $<.05$. Relative risk (RR) ratio and 95% confidence intervals (CIs) were calculated for comparison of receipt of procedures, medications, and location of death.

**RESULTS**

The cohort comprised 24,342 children who died $\geq 5$ days after hospitalization. Of these, 919 (4%) had a documented code for PC services during their terminal hospital admission. Demographics and clinical features in Table 1 compare children with and without PC services. Older patient age was associated with increasing receipt of PC services. Children identified as African American received PC significantly less often than white or Hispanic children. Although the majority of all children had government-sponsored insurance, children with PC services were more likely to be insured privately. Children with documented receipt of PC services had significantly lower median LOS (17 vs 21 days) and average daily charges ($9348 vs. $11,806) compared with those without documented PC services. Over the study period, use of the PC code increased significantly, from 94 (1%) children who died in 2001–2004, compared with 539 (8%) who died in 2009–2011. Receipt of PC services varied significantly by MDC. Infants with conditions of the newborn period accounted

| TABLE 1 Select Demographic and Clinical Features Comparing Children Who Died $\geq 5$ Days After Hospital Admission by Receipt of PC Services |
|---------------------------------|------------------|------------------|------------|
| No PC Code, $N = 23,425$, $n$ (%) | PC Code, $N = 919$, $n$ (%) | $P$ |
| Age $^a$ | 49 (0–1238) | 1000 (59–3647) | $<.001$ |
| 0–30 d | 11 100 (48) | 218 (2) |
| 31–365 d | 4303 (18) | 164 (4) |
| 1–3 y | 194 (8) | 97 (11) |
| 4–12 y | 3223 (14) | 264 (29) |
| 13–18 y | 2853 (12) | 176 (19) |
| Gender $^b$ | | | .49 |
| Male | 12 866 (55) | 488 (53) |
| Female | 10 552 (45) | 431 (47) |
| Race $^b$ | | | $<.001$ |
| White | 9822 (42) | 407 (44) |
| Black | 4545 (19) | 105 (11) |
| Hispanic | 4222 (18) | 198 (22) |
| Other | 3533 (15) | 168 (18) |
| Payer | | | $<.001$ |
| Private | 6412 (27) | 281 (31) |
| Other | 4472 (19) | 122 (13) |
| Medicaid | 12 312 (53) | 502 (55) |
| Medicare | 227 (1) | 14 (2) |
| LOS (d) $^c$ | 21 (10–47) | 17 (5–38) | $<.001$ |
| Average daily charges adjusted for geography $^c$ | $11,806 (8017$–$18)$ | $93548 (6807$–$15)$ | $<.001$ |
| Year of death | | | $<.0001d$ |
| 2001–2004 | 7323 (31) | 94 (10) |
| 2005–2008 | 9729 (42) | 286 (31) |
| 2009–2011 | 6371 (27) | 539 (58) |
| MDC | | | $<.001$ |
| Newborns/other neonates with conditions originating in the perinatal period | 9693 (41) | 183 (20) |
| Respiratory system D/D | 3153 (14) | 150 (16) |
| Circulatory system D/D | 2594 (11) | 75 (8) |
| Nervous system D/D | 167 (7) | 159 (17) |
| Lymphatic, hematopoietic, other malignancies, chemotherapy, and radiotherapy | 1257 (5) | 85 (9) |
| Infectious and parasitic diseases, systemic or unspecified sites, and HIV infections | 1068 (5) | 58 (6) |
| Digestive system and hepatobiliary system/pancreas D/D | 1395 (6) | 43 (5) |
| Other | 2584 (11) | 166 (18) |
| CCC | 19 884 (85) | 851 (83) | $<.001$ |

$^a$ Median, IQR.

$^b$ Five were missing.

$^c$ One thousand three hundred one were missing.

$^d$ $x^2$ for linear trend.
for 41% of all deaths, but only 2% of these infants had documentation of PC services. PC services were more common among children with diseases of the nervous system (9%) and the hematopoietic system/malignancies (6%) compared with those with infectious diseases (5%) or diseases of the gastrointestinal system (3%). CCCs were present in 85% of the study cohort. Those with CCCs compared with patients without CCCs were just over twice as likely to have documented PC (RR 2.2; 95% CI 1.7–2.8).

Table 2 outlines differences in procedures and medications received and the care setting. Overall, patients with the PC code received significantly less mechanical support, invasive monitors, supportive care such as total parenteral nutrition, and operating room charges. Noninvasive mechanical ventilation was more common in children with PC codes (RR 1.6; 95% CI 1.3–1.9). Children with a PC code received significantly fewer medications including sedatives and analgesics. Finally, fewer patients with involvement of PC services were admitted to an ICU (RR 0.29; 95% CI 0.26–0.32) and fewer died in an ICU (RR 0.64; 95% CI 0.64–0.72).

As shown in Table 1, receipt of PC services increased with patient age. However, this pattern differed across MDCs. A significant increase of receipt of PC with increasing age was seen for those with diseases of the respiratory system (3% in infants; 31 days–1 year) to 7% in teens (13–18 years), diseases of the circulatory system (2% in infants to a high of 6% in 4–12 year olds), and infectious diseases (4% in infants to 7% in teens). Although receipt of PC was greater among children dying with lymphatic/hematopoietic diseases (6%) and neurologic disorders (9%), receipt of PC did not increase with age.

Children with diseases of the respiratory, nervous, and lymphatic/hematopoietic system experienced greater differences in their end-of-life care, with those with PC receiving relatively fewer invasive interventions. Differences were less pronounced for those dying from neonatal conditions, diseases of the cardiovascular, gastrointestinal systems, or infectious diseases (data not shown). For instance, among children dying with diseases of the lymphatic/hematopoietic system, receipt of mechanical ventilation was 22% for those with PC compared with 75% for those without PC involvement, whereas among those dying from conditions of the newborn period, mechanical ventilation was used to treat 93% with PC compared with 98% without PC involvement. PC involvement and death in an ICU also differed across MDCs. Among those receiving PC, only 21% with diseases of the lymphatic/hematopoietic system died in an ICU compared with 66% of children with diseases of the respiratory system.

Differences in use of invasive therapies between patients with and without PC involvement generally increased with patient age. For example receipt of mechanical ventilation differed less for infants (31–365 days; 84% vs 95%) than for older children (ages 4–18 years; 39% vs 81%). A similar pattern was seen for death in an ICU (infants, 77% vs 90%; children 4–18 years, 56% vs 77%).

**DISCUSSION**

This study compares demographic and clinical features of children who died in a children’s hospital with and without PC. We found that <4% of children who died after ≥5 days received PC. In this cohort, PC was more common in older patients and was associated with fewer days of hospitalization before death. Receipt of PC has increased over the past decade and varied among MDCs. Overall, children who received PC were less likely to have invasive interventions, received fewer medications, and were less likely to die in an ICU.
In our study, only 4% of patients who died received PC. This percent is lower than other contemporary reports. Although the completeness and accuracy of the billing codes cannot be verified, all hospitals had patients with the PC V-code, so it is unlikely that the low percent of patients is due to lack of coding for services. If the billing codes were missing in some cases, they are likely to be randomly missing, so the trends found should be representative. Low utilization cannot be explained by unexpected deaths because only children who died after 5 days of hospitalization were included. The initial low proportion of PC use could be due to the time period evaluated. Guidelines for pediatric PC were not issued until 2000, and the majority of hospitals did not have patients with a V-code during the first years of the study, which may reflect an absence of PC services. Also, children who were discharged before death under hospice care were not included in our analysis, thus underestimating the overall use of PC.

Among dying hospitalized children, PC use increased with age. Older children, in general, received fewer invasive procedures, but this was more pronounced in the PC group. Children with diseases of the respiratory system, circulatory system, and infectious disease were more likely to receive PC as they aged. The reasons for this are unclear. Most of the children in the cohort had CCCs, and thus they likely had an established diagnosis and adequate time for a PC referral before death. Historically, PC was considered only after all possible curative measures had been exhausted. In 2000, the American Academy of Pediatrics made a statement supporting the concurrent use of PC and curative care for children from the time of diagnosis of a life-threatening illness. Previous studies have demonstrated a delay in referral to PC based on the belief that a referral is not needed until curative treatment is no longer the sole goal. More recently PC and curative care are being delivered concurrently; however, further investigation is needed to determine when, in the course of illness, children are referred to PC.

Children receiving PC had lower LOS and average daily charges. Children without PC services lived a median of 4 days longer before death, and their daily charges were ~$2500 more. This amount is slightly higher than previous estimates but is consistent with other studies that found that PC involvement, while emphasizing patient and family care preferences, is associated with cost reduction.

Our study showed that coding for PC increased over the study period, which is consistent with recent studies showing an increase in PC programs over the past 10 years. However, availability of a PC team does not equate to widespread use. Johnston found that in Canada, although 88% of the centers evaluated had PC teams, <16% of patients received these services at the time of their death.

Our data show that specific disease groups are associated with higher receipt of PC. For example, children of all ages with neurologic disorders were more likely to receive PC. This is similar to findings by Feudtner, who found that neurologic disease was a common diagnosis among children receiving PC. MDs associated with less use of PC were neonatal disease (2%) and circulatory disease (2% to 6% by age group). Similar to other studies, most of the children were <1 year old (65%), with the majority being <30 days old. Few of these infants had documented receipt of PC. Many NICUs have dedicated social work and support care services as part of the care team. Although these services provide extensive family support while the infant is in the ICU, families might benefit from the continued support provided by a PC team for infants surviving the neonatal period. It is unclear why so few children with circulatory disease received PC.

Children with PC involvement received fewer medical interventions compared with children without PC, except for noninvasive mechanical ventilation. Receipt of mechanical ventilation among patients without PC was 92%, which is similar to other studies. Differences in receipt of invasive procedures were more pronounced in older children compared with infants, who received the most interventions. Children with specific MDC were more likely to receive interventions (diseases of neonatal period, the cardiovascular, infectious, or gastrointestinal systems). This identifies areas in which subspecialists can optimize patient care by promoting early involvement of the PC team.

Another important area for end-of-life care is pain control. Just under half of all dying children received analgesics in their final 4 days of life, and only one-third received sedatives. Parents and some providers are concerned that giving higher doses of these medications may accelerate the dying process; however, Janvier found that time to death after withdrawal of life-sustaining treatments did not change when increases in these medications were given. Our results differ from previous reports showing greater analgesic and sedative use at the time of death. It is difficult to fully explain the lower use of these medications. It is possible that children receiving PC services who were not ventilated or undergoing invasive procedures did not require sedation and pain control. It is also possible that there was incomplete documentation of administered medications, although we assessed receipt in the last 4 days.
REFERENCES

ZIP CODES AND ME: I was at the checkout counter the other day when, as so often happens, the woman at the register asked for my zip code. I am always irked by this request. After all she already had my credit card and a photo identification card. Sometimes, after sliding my credit card at a self-service gas pump, I am asked for my zip code to ensure that the card being used is not stolen. In those situations I always type in my correct zip code. It turns out, however, that my hesitancy to give retail store clerks my correct zip code is well-founded. As reported on CNN (Money: April 18, 2013), the 5-digit zip code is used to confirm my identity and eventually link my purchase with other personal traits and habits. The retail store gets the name of the customer from the credit card. The zip code is used to confirm that the purchaser is the Bill Smith from Burlington, Vermont rather than Cedar Rapids, Iowa. Now the retailer can track and analyze purchasing habits and predict what I am doing or will need in the future. If I buy rakes and shovels, computer modeling would suggest that I am engaged in a project around the house. The retailer can begin targeted advertising or sell the information to data brokers. Data brokers store vast amounts of information about each of us. The largest data broker in the US claims that it has stored the age, marital status, education and income levels, political leanings, and even hobbies on almost 200 million individuals. The information about me can be packaged and sold to banks, other retailers, and even social media sites. Clearly, there is little privacy in the digital age. I try my best to preserve what little I have. Because customers are not required to give their home zip code to complete their purchase, I always reply to the sales clerk’s request with a smile and a firm no. You might consider doing the same.

Noted by WVR, MD
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