



Patterns of Hospice and Home-Based Palliative Care in Children: An Ohio Pediatric Palliative Care and End-of Life Network Study

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Objective To describe the demographic and clinical characteristics of a cohort of patients referred to pediatric hospice and home-based palliative care (HBPC) programs across Ohio in 2016.

Study design Retrospective cohort study of patients referred to hospice/HBPC from 3 pediatric palliative care programs in Ohio in 2016. Demographic and clinical data were extracted from the medical record and analyzed with descriptive statistics.

Results There were 209 patients referred: 49 (24%) to hospice and 160 (77%) to HBPC. The most common diagnoses were genetic/chromosomal syndromes (23%), neurologic or neurodegenerative conditions (23%), and cancer (21%). Durable medical equipment use was frequent (85%), with gastrostomy or jejunostomy tubes (22%) the most common. Most patients (64%) retained full-code resuscitation status. Fifty-seven patients (27%) died before July 1, 2018: 37 in hospice (18% of the overall cohort, 65% of decedents) and 20 in HBPC (10% of the overall cohort, 35% of decedents). Sixty-seven percent of hospice and 40% of HBPC patients died at home.

Conclusions Pediatric hospice and HBPC programs serve a diverse cohort of patients. Patients referred to pediatric HBPC programs commonly die and are likely to die at home despite not being enrolled in hospice care. The high proportion of decedent HBPC patients indicates that the notion of hospice vs palliative care may present a false dichotomy in many children with life-limiting conditions. Reimbursement models for HBPC should reflect the clinical similarity to hospice in the care of children with life-limiting illnesses. (*J Pediatr* 2020;225:152-6).

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As medical therapies advance, many childhood illnesses that were previously fatal have been transformed into chronic, life-limiting diseases into late childhood and young adulthood.¹ For such patients, the length of illness varies widely, making prognostication difficult.² Developing a plan to address goals of care often requires concurrent curative and palliative modalities.² Pediatric hospice and home-based palliative care (HBPC) is defined as the seamless integration of hospice or palliative care in the patient's home as well as outpatient and inpatient settings.³ Hospice and HBPC programs provide care for children with life-limiting conditions and their families across the arc of their diseases, through their deaths and into bereavement care. When these programs are separated, they may vary in breadth and depth of services offered, yet commonly provide nursing support, pain and symptom management, continuity and coordination of care, assistance with durable medical equipment and medications, and ancillary services such as child life, music therapy, art therapy, chaplaincy, social work, and bereavement care.⁴

Pediatric HBPC differs from inpatient palliative care in important ways. HBPC teams typically rely less on physician and nurse practitioner support and more on nursing care and dedicated psychosocial support than inpatient palliative care teams.¹ The acuity of care differs. Children who receive palliative care in the hospital are acutely ill, whereas those who receive care for in HBPC programs may be relatively stable for years before an acute event occurs or they approach end of life.¹ The care plans developed longitudinally in the home vs the hospital reflect these contrasting circumstances.¹

Based on the traditional adult model of care, pediatric hospice enrollment requires a prognosis of 6 months or less, which presents a challenge for pediatric physicians owing to the unpredictable natural history of childhood illnesses and limits the cohort of patients who are eligible.^{1,2} In contrast, pediatric HBPC allows for the provision of support to a broad spectrum of patients with life-limiting conditions, without tying eligibility to prognosis. This pediatric model shares many similarities to adult community-based palliative care, which

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HBPC Home-based palliative care
OPPEN Ohio Pediatric Palliative Care and End-of-Life Network

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is also a longitudinal delivery model integrating interdisciplinary care across care settings to patients with life-limiting illnesses.⁵ These children may transition to hospice care when care needs change and/or they meet hospice eligibility criteria.⁵ In the adult setting, community-based palliative care has been shown to decrease hospitalizations and length of stay, increase hospice utilization, decrease the cost of care, and improve symptom burden and quality of life.⁶⁻¹⁵ Few studies have evaluated these outcomes in pediatric hospice or HBPC.

The Ohio Pediatric Palliative Care and End-of-Life Network (OPPEN) is a consortium of pediatric hospice and palliative programs, including several dedicated pediatric hospice and HBPC programs. Using the infrastructure of OPPEN, the primary goal of this study was to characterize a cohort of patients who were referred to hospice and/or HBPC in 2016.

Methods

All research activities were conducted with approval of the institutional review boards at 3 study sites (Cincinnati Children's Hospital Medical Center, Nationwide Children's Hospital, and Akron Children's Hospital). A waiver of informed consent was obtained for this study because the data obtained were already part of the patients' medical records. The Palliative Care Division's database at each of the 3 children's hospitals was queried to identify patients who were referred to hospice or HBPC programs between January 1, 2016, and December 31, 2016.

Each site has its own HBPC program; the programs at Cincinnati and Nationwide also provide hospice care. All patients who are seen by the inpatient palliative care team at Akron are referred to their HBPC program; all members of the inpatient palliative care team (physician, advanced practice nurse, social work, pastoral care, psychology, child life specialist) may visit the patient at home. Criteria for referral to HBPC at Nationwide and Cincinnati are that the patient has experienced a recent clinical decline or is expected to decline significantly in the near future, and the family has expressed a desire to limit life-sustaining medical treatments in some way. The Nationwide hospice and HBPC programs offer the same services: intermittent nursing and physician visits, social work, pastoral care, child life specialist, music therapy, and massage therapy. The Cincinnati hospice and HBPC programs both offer all of these services as well as art therapy. The baseline frequency of visits at referral to hospice for the Nationwide and Cincinnati programs is determined by requirements for hospice patients. HBPC patients are typically seen less frequently than hospice patients, unless they have acute needs or are dying. HBPC patients who die at home in the Nationwide and Cincinnati programs receive the same services as hospice patients who die at home.

Study inclusion criteria were all patients cared for at each of the 3 sites who were newly referred to hospice or HBPC services during the 12-month study period. Patients referred

to private hospice programs were included. There were no exclusion criteria. The primary source of data was the electronic medical record at each primary site at the time of referral. Patient data regarding care received from private hospice organizations were not accessible. Once all 3 sites had submitted data, the entire cohort was reviewed and patient status (alive or dead) was updated as of July 1, 2018, as well as date and location of death, when applicable.

Specific data collected included patient name, date of birth, sex, referral diagnosis, date of enrollment, date of death, race/ethnicity, religion, payor status, primary language spoken in the home, location of death, code status, specific durable medical equipment used in the home, specialty of the physician managing home care, program or organization to which the patient was referred, and type of care received (hospice vs HBPC). Referring diagnoses were categorized using the complex chronic conditions classifications (version 2), based on *International Classification of Diseases, 10th edition*, codes.¹⁶ Age at referral to hospice or HBPC and age at death were calculated from other dates. All these data were compiled into a retrospective registry using REDCap.¹⁷ Descriptive statistics were generated, including means with SDs and medians with ranges for continuous variables, and frequencies and percentages for categorical variables for all study participants.

Results

A total of 209 records were obtained: 160 patients referred to HBPC and 49 referred to hospice programs. Nine patients had both a HBPC and a hospice record; all were patients at Akron, which co-enrolled them into their HBPC program and private hospice organizations. Descriptive demographic and clinical data characterizing patients receiving hospice or HBPC at these sites in 2016 are provided in the [Table](#). The overall cohort was 44% female, but only 33% of hospice patients were female. The median age at referral for the overall cohort was 2 years (range, 0-38 years for overall and HBPC; range, 0-31 years for hospice). The cohort was primarily white (73%), non-Hispanic (96%), and English speaking (96%); 54% of patients had private insurance and 43% had public. The median age at death was 9 years for the overall cohort, 3 years for hospice, and 13.5 years for HBPC. A total of 57 patients died, 37 in hospice and 20 in HBPC.

The most common diagnoses encountered were genetic or chromosomal syndromes (23%); neurologic, neuromuscular, or neurodegenerative conditions (23%); and cancer (21%). There were some diagnostic differences between the hospice and palliative care groups, with cancer being more common in the hospice group (41% vs 14%) and prematurity more common in the palliative care group (15% vs 2%). Likewise, the managing physician was most commonly a palliative care physician for HBPC, with an oncologist more likely to manage hospice than HBPC patients.

Durable medical equipment was used in 85% of the overall cohort. The majority of patients were full code at the time of

Table. Demographic and clinical characteristics of study patients

Characteristics	All	Hospice	HBPC
All patients	206 (100)	49 (24)	160 (76)
Female sex	79 (44)	9 (33)	68 (46)
Race			
White	153 (73)	34 (74)	117 (74)
African American	33 (16)	5 (11)	27 (17)
Asian	4 (2)	0	4 (3)
Mexican	1 (1)	0	1 (1)
Native Hawaiian	2 (1)	0	1 (1)
Unknown	16 (8)	7 (15)	9 (6)
Ethnicity			
Hispanic	8 (4)	4 (9)	4 (3)
Non-Hispanic	200 (96)	41 (90)	155 (98)
Unknown	1 (1)	1 (2)	0
Payor			
Public	87 (43)	18 (39)	69 (44)
Private	108 (54)	25 (54)	83 (53)
Private or international	6 (3)	3 (7)	3 (2)
Tricare (military care)	1 (1)	0	1 (1)
Other	3 (2)	0	3 (2)
Language			
English	201 (96)	42 (91)	155 (98)
Spanish	2 (1)	2 (4)	0
Other	6 (3)	2 (4)	4 (3)
Religion			
Jewish	1 (1)	0	1 (1)
Muslim	1 (1)	0	1 (1)
Protestant	24 (12)	5 (11)	19 (12)
Nondenominational	79 (38)	13 (28)	65 (41)
Catholic	22 (11)	2 (4)	20 (13)
Anabaptist	5 (2)	0	5 (3)
Unknown/did not disclose	46 (22)	12 (26)	34 (21)
None (atheist)	31 (15)	14 (30)	14 (9)
Diagnosis			
Genetic/chromosomal syndrome	49 (23)	11 (24)	38 (24)
Cancer/malignancy	43 (21)	19 (41)	22 (14)
Neurologic, neuromuscular, neurodegenerative	48 (23)	12 (26)	36 (23)
Pulmonary	7 (3)	0	7 (4)
Cardiac	5 (2)	0	5 (3)
Emergency/trauma	9 (4)	2 (4)	7 (4)
Prematurity	25 (12)	1 (2)	24 (15)
Other	8 (4)	1 (2)	7 (4)
Managing homecare subspecialty			
General pediatrician	5 (3)	3 (8)	2 (1)
Oncologist	8 (4)	7 (18)	1 (1)
Complex care pediatrician	5 (3)	3 (8)	2 (1)
Pulmonologist	2 (1)	0 (0)	2 (1)
Pain management physician	4 (2)	2 (5)	2 (1)
Other	6 (3)	0 (0)	6 (4)
Palliative care physician	150 (75)	6 (16)	144 (91)
Hospice physician (other)	17 (9)	17 (45)	0
DME in use at referral	96 (85)	27 (75)	69 (89)
Oxygen	10 (5)	5 (10)	5 (3)
Ventilator	5 (2)	0 (0)	5 (3)
Ventilator or bilateral positive airway pressure	8 (4)	2 (4)	6 (4)
Gastrostomy or jejunostomy tube supplies	47 (22)	21 (43)	26 (16)
Code status			
DNR-CCA	4 (2)	0 (0)	4 (3)
DNR or DNR-CC	52 (25)	16 (33)	36 (23)
Limited	8 (4)	0 (0)	8 (5)
Full	133 (64)	31 (63)	102 (65)
None or unknown	10 (5)	2 (4)	7 (5)
Decedent	57 (100)	37 (65)	20 (35)

(continued)

Table. Continued

Characteristics	All	Hospice	HBPC
Location of death			
Home	33 (58)	25 (67)	8 (40)
Hospital	21 (37)	9 (24)	12 (60)
Hospice	1 (1)	1 (3)	0
Unknown	2 (4)	2 (6)	0

DNR, do not resuscitate; *DNR-CCA*, do not resuscitate-comfort care arrest (an order to not perform cardiopulmonary resuscitation if the patient has no pulse and is not breathing); *DNR-CC*, do not resuscitate-comfort care (an order to not perform cardiopulmonary resuscitation, or initiate or escalate life-sustaining medical treatment, at any point even before the heart or breathing stops).

referral (64% overall; 61% hospice and 65% HBPC). Of decedent patients with a known location of death, 60% died at home, 2% at a hospice facility, and 38% in the hospital. Hospice patients were most likely to die at home (67%); 44% of HBPC patients died at home.

Discussion

The primary goal of this study was to characterize the cohort of patients referred to pediatric hospice or HBPC programs across Ohio in 2016. We found that patients enrolled in hospice or HBPC programs most commonly carried the diagnoses of genetic or chromosomal abnormalities and neuromuscular or neurodegenerative diseases, frequently used durable medical equipment in the home, and were most commonly full code resuscitation status at the time of referral.

These findings are consistent with studies of children receiving palliative or hospice care. Feudtner et al described a large sample of patients who received pediatric palliative care across 6 North American sites.¹⁸ The most common diagnoses were again genetic or congenital (41%), neuromuscular (39%), and cancer (20%). The majority were on multiple medications and used some form of durable medical equipment on an ongoing basis outside the hospital setting. There are similarities of this cohort to studies evaluating the population of children who use hospice care. One large study of pediatric and adult patients in hospice care found that pediatric patients were 4 times more likely to have an enteral feeding tube than adults, that 60% of pediatric patients were full code resuscitation status at the time of hospice enrollment, and that pediatric patients were one-half as likely to have a do not resuscitate order compared with adults who used hospice.¹⁹

An important finding of our study was the relatively high proportion of children who died while enrolled in HBPC programs. Although most of the patients who died in our cohort were in hospice, and children referred to hospice programs frequently died, 35% of the patients who died were enrolled in HBPC rather than hospice programs at the time of their death. This is nearly twice the frequency of adults who die while receiving community-based palliative care rather than hospice care.²⁰

Many of the children in HBPC who died experienced death at home. Friedrichsdorf et al evaluated location of death in children with cancer who used HBPC and found that those children were more likely to die at home than those who did not.²¹ Similarly, a retrospective study of 224 children enrolled in the community-based program CompassionNet found that 39% of decedent patients died at home while enrolled in the program.² When compared with children summarized by the National Hospice and Palliative Care Organization, children in CompassionNet died at home more frequently across all age categories than children who died overall.²²

However, death at home is not a stand-alone indicator of high-quality end-of-life care for children. The opportunity to plan location of death, and the ability to accomplish that plan might be better quality measures.²³ Instead, we highlight the high frequency of home death across our cohort as an exemplar of the false dichotomy of conceptualizing children with life-limiting conditions as being most appropriate for hospice vs palliative care, as though these are clearly distinct constructs. The nature of a child's life-limiting illness may change acutely or slowly, as may their family's goals. Some parents also have difficulty accepting the term hospice and may be more likely to accept instead HBPC. When change happens, our findings support the idea that patients benefit from flexible, longitudinal, home-based support in programs equipped to deliver high-quality end-of-life care. Anecdotally, when patients are not expected to die but become acutely ill and desire to die at home, there may be little to no clinical value in electing a hospice benefit before their death if they are well-integrated into HBPC programs that provide essentially the same services as a hospice. Hospice is an established, well-regulated care delivery model with specific payment structures and quality guidelines.²⁴ The emerging pediatric HBPC model of care currently has little structure for reimbursement. Payment models should evolve to reflect the clinical reality of caring for children with unclear prognoses by providing reimbursement for home-based nursing, medical, and psychosocial support, regardless of whether the support is labeled hospice or palliative care.

We found no difference in diagnostic categories between patients who died with hospice care and those who died with HBPC. Clinically, some populations of children are more easily certified as eligible for hospice care according to the traditional definition that the child has a prognosis of 6 months or less if the disease follows its normal course. A child with progressive cancer who has no further chemotherapeutic options is very likely to die within several months. An infant with a severe brain malformation who experiences apneic events and whose parents forgo positive pressure ventilation may also be reasonably expected to die within weeks to months. Even that infant, however, may stabilize over time and live for months to years, during which time the parents' goals may shift. This scenario is not uncommon in pediatric palliative care. The question of whether and when to discharge that child from hospice care can cause difficulty and stress for both families and the hospice team. The

availability of HBPC may ease this transition and may also allow programs that are not able to receive reimbursement for concurrent care to provide high-quality, home-based care to children as they die. The underlying problem is a system that requires certification of a time-limited prognosis, traditional in adult hospice care, to access palliative care for a child, not that the child has survived or that the family desires concurrent treatment-directed care and hospice care. Adult medical criteria are not applied to children elsewhere in medicine. Pediatric palliative and hospice providers should advocate for the creation and maintenance of systems that are medically appropriate for children with life-limiting illnesses, including criteria for home-based care that reflect the reality of pediatric chronic illness.

Our study has limitations. All patients were seen at pediatric palliative care centers in a single state in the Midwest, which may limit generalizability to the country as a whole. Additionally, our sample is primarily white and non-Hispanic, which may limit external validity in other, more diverse, populations. This limitation is, however, consistent with other studies evaluating children receiving palliative care.¹⁸ Our study was not designed to evaluate whether patients received concurrent treatment-directed therapy and hospice care. As with any retrospective chart review, some data were missing, limiting the sample size available for some analyses. For example, we were unable to assess which complement of palliative care or hospice services children were receiving, where the family preferred death, and whether the patient died in the preferred location. Data were collected solely from the electronic medical record in pediatric hospitals. We were unable to collect follow-up data from private hospice programs, limiting our understanding of patients who received care from those programs.

Our findings illustrate the flexibility of HBPC programs in caring for children with uncertain prognoses as care needs change. The high proportion of decedent HBPC patients indicates that the notion of hospice vs palliative care may be a false dichotomy in many children with life-limiting conditions. Reimbursement models for HBPC should evolve to reflect the clinical reality of caring for children with life-limiting illnesses such that the care model fits the child and family, rather than necessitating that the child fit the traditional model designed for elderly adults. ■

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Data Statement

Data sharing statement available at www.jpeds.com.

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