Characteristics of a Pediatric Hospice Palliative Care Program Over 15 Years

WHAT’S KNOWN ON THIS SUBJECT: Palliative care is an increasingly important element of pediatric care for children with noncurable, terminal conditions. Freestanding hospices represent one model of care provision; however, little research on this approach has been conducted.

WHAT THIS STUDY ADDS: This report documents the experience of North America’s first freestanding hospice over 15 years to better understand the characteristics of children and families enrolled and to establish baseline information for future studies and program planning.

abstract

OBJECTIVES: Pediatric palliative care has seen the adoption of several service provision models, yet there is minimal literature describing them. Canuck Place Children’s Hospice (CPCH) is North America’s first freestanding pediatric hospice. This study describes the characteristics of and services delivered to all children on the CPCH program from 1996 to 2010.

METHODS: A retrospective review of all patient medical records CPCH was conducted. Analyses examined trends and correlations between 40 selected data points: linear regression modeling was used to assess trends over time; t tests were used to examine significant associations between independent means; and the Kaplan-Meier method was used to measure survival probabilities.

RESULTS: The study cohort included 649 children. The majority of diagnoses belonged to cancers (30%), and diseases of the neuromuscular (20%), and central nervous systems (18%). The majority of deaths occurred among the cancer (45%), central nervous system (15%), and metabolic disease groups (14%). By study end date, 24% of children were still alive, 61% died, and 15% transitioned to adult services (more than half of whom were cognitively competent). On average, 1024 days were spent on the CPCH program (median = 301). The majority of inpatient hospice discharges were for respite (82%); only 7% were for end-of-life care. Location of death was shared between CPCH (61%), hospital (22%), and home (16%).

CONCLUSIONS: Diagnostic groups largely determine the nature and magnitude of services used, and our involvement with pediatric life-threatening conditions is increasing. Reviews of pediatric palliative programs can help evaluate the services needed by the population served. Pediatrics 2014;134:e765–e772
In the United States, an estimated 500,000 children are living with a “life-threatening condition” (LTC), with 15,000 dying each year of conditions that warrant pediatric palliative services. Although prevalence is unknown in Canada, in 2005 alone, 2300 children died of LTCs. In the face of nontreatable conditions, or when a cure has not succeeded, pediatric palliative care (PPC) attempts to improve the quality of life through the prevention and relief of suffering by identifying and treating physical and psychosocial symptoms. PPC encompasses more than the final weeks to days of life, moving upstream to the long period of chronic complex care. PPC should ideally be provided by a multidisciplinary team and extend throughout a child’s life and into a family’s bereavement.

PPC can be delivered in various settings, including community, hospitals, hospice, and at home. In the United Kingdom, where the modern pediatric hospice-palliative care movement began with the founding of Helen House in 1982, the freestanding hospice approach has been commonly employed. Other countries, including the United States, typically emphasize hospital inpatient consultation and home-hospice care. Canada has adopted a blended model, with both hospital-community programs and separate “freestanding” inpatient programs that provide respite, symptom management, and end-of-life (EOL) care. Currently, 6 freestanding hospices in Canada are in operation. Although there is debate regarding the optimal location of care, there is a paucity of research describing PPC program characteristics to better inform that debate.

Referrals to palliative care teams are increasing over time for all diagnostic categories. Although the freestanding approach is gaining importance, little research on this model has been conducted to inform how delivery of care is to be proposed, improved, and/or expanded. Few descriptions of pediatric freestanding hospice programs exist. In an analysis of Helen House, important information on admission, type of care provided (terminal care versus relief care), and distance from home was provided. Vadeboncoeur et al descriptively reviewed referral sources, diagnoses, and reasons for discharge for patients referred to the palliative care team at the Children’s Hospital for Eastern Ontario from 1999 to 2007. Data were included on the operations of the freestanding hospice associated with this program (Roger’s House), which began operations in 2006. To build knowledge in this field, it is important to review pediatric palliative programs and build evidence to evaluate the benefits such programs offer. This report describes the activities of a freestanding PPC hospice. The aim of this study is to document the population cared for by North America’s first freestanding hospice over a 15-year span from inception to maturity; to better understand the characteristics of children and families enrolled; and to establish baseline information for future studies and program planning.

**Program Description**

In November 1995, Canuck Place Children’s Hospice (CPCH) opened its doors as the first freestanding children’s hospice in North America. To date (December 31, 2013), the CPCH program has provided care to ~826 children (ages 0–19) and their families who live in the province of British Columbia, Canada. In 2013 alone, CPCH provided clinical care to over 250 children and bereavement services to another 250 families. We estimate that in any given year, we provide care to ~28% of the eligible population in our catchment area. Any child with an LTC is eligible to be on the program. LTC is defined as either an acute or chronic condition where the likelihood of dying before the age of independent adulthood is high, and where either curative attempt is not succeeding or no cure exists. Referrals are accepted from any source, although most are by specialist physicians. Nonemergency referrals are reviewed weekly by an intake committee, whereas urgent referrals can be accepted immediately post physician–nurse assessment. The committee utilizes clear guidelines for decision-making, which include information on the diagnosis itself (obvious risk of death before reaching adulthood as informed by expert opinion, scientific literature, and epidemiology); the child’s individual course of disease; the presence of complications; and the readiness of the family to be on a palliative care program. Our admission criteria are informed by a conceptual model developed by the Association for Children With Life-Threatening or Terminal Conditions and Their Families (now Together for Short Lives) that describes the 4 broad groups of illnesses characterizing PPC (Supplemental Appendix 1).

The spectrum of care provided at CPCH encompasses a range of services including, but not limited to, the following: respite-family care; psychosocial care; pain and symptom (P&S) management; advance care planning; EOL; and bereavement care. The inpatient hospice is licensed for 9 beds and has 4 family suites. Families can receive up to 20 nights per year of scheduled respite stays. Workload, staffing, and the number of children in-house are dictated by a Nursing Workload Measurement Tool and Acuity Scale developed by our clinical and management teams. A description of this tool and how it guides operations and staffing can be found in Supplemental Appendix 2. The clinical staff consists of physicians, registered nurses (RNs), licensed practical nurses (LPNs), respiratory therapists, personal...
care aides (PCAs), and counsellors. Psychosocial support is provided to siblings and parents as well. Typically, the CPCH budget supports 3 RNs, 1 LPN, and 1 PCA to be present on each shift. A respiratory therapist is present for children who are dependent on ventilators. One physician, who has a presence in-house, is on call daily. Urgent cases are never turned away as we provide unlimited stays for symptom management and EOL care.

In the hospice, there are spaces for art, music, and play therapy. Meals and laundry services are provided to families in-house. A schoolroom staffed by the Vancouver School Board provides educational continuity to school-aged patients and siblings. Recreation therapy occurs both in the hospice and through community outreach events. Bereavement services are a large component of the program, serving families regardless of location of death. CPCH is recognized as the expert PPC in the province, and our clinical team is the designated consultation provider in the province, and our clinic is recognized as the expert PPC for families regardless of location of death. Bereavement services are a large component of the program, serving families regardless of location of death.

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The CPCH program is available at no cost to families. While working closely with the publicly funded health system, the CPCH program is independent with its own board of directors. Funding is provided through both government and charitable funds, with the majority being privately donated. Supplemental Appendix 3 provides a breakdown of our operational costs and budget over the past decade. Approximately 70% of per patient day costs are for clinical support (Supplemental Appendix 3, Table 2). Government funding through the publically subsidized health care system is determined by acuity (the CPCH acuity scale is described in Supplemental Appendix 2) and has supported 32% of our operational costs over the last 10 years. Key fundraising professionals work with a donor-centric philosophy that support strong fundraising techniques to meet the remainder of CPCH’s budgetary needs. Our operations are made possible by a team of over 300 volunteers. Approximately 85 volunteers are at the hospice each week providing support in practical roles (eg, garden, reception, fundraising, and kitchen). Family volunteers work directly with children and families, providing one-to-one companionship to the children and their siblings but not clinical care.

**METHODS**

A retrospective review of all CPCH patient medical records from 1996 to 2010 was conducted. The following information for each patient was extracted: demographics; diagnoses; admissions/discharges; advance care planning; EOL care; and transition off program into adulthood. The specific data items that were collected are shown in Supplemental Appendix 4. The medical charts did not contain information on family financial status or ethnicity given the publicly funded nature of the health care system and the availability of cultural workers and translators when required. A trained Master’s level nursing student conducted the chart reviews. Identifiers were removed and unique codes were assigned once information was entered into a database. Sample data were re-entered by a second, similarly trained Master’s level nursing student to enhance accuracy.

The research team met with members of the care team, which included senior management, nurses, physicians, counsellors, and therapists, who were asked to identify areas of investigation they considered of interest and relevance to their understanding of the population for which they care. Analyses presented in this study were informed by the topics identified as clinically relevant to the PPC practitioners working at CPCH.

Descriptive analysis of all variables was conducted. We examined trends between the 7 diagnostic groups we use internally to categorize the children on our program. (Supplemental Appendix 5). To account for year-to-year variations, lines of best fit were used when graphing. Linear regression modeling was used to assess trends over time; t-tests were used to examine significant associations between independent means. The Kaplan-Meier method was used to measure survival probability in the first 2 years of acceptance on program (1996–2008). All analyses were conducted at $P = .05$ level of significance. For each analysis, children were omitted if the specific field of investigation was marked as “unknown,” “unclear,” or “no data.” The majority of such cases were noted to be from the oldest charts.

**RESULTS**

Of the 672 cases reviewed, 649 were eligible for analysis (14 were never accepted onto program, 6 post 2010 acceptances, and 3 duplicate entries). Table 1 displays the demographic characteristics of these children. The gender distribution can be explained by the high number of boys on program with Duchenne muscular dystrophy, an X-linked recessive condition. Since 2007, this gap has narrowed as our referral and acceptance patterns changed in response to improvements in longevity for these patients. Over 15 years, 194 children with cancers were accepted (39% solid tumors, 38% brain tumors, and 23% hematologic/lymphatic cancers). The proportion of children with chromosomal/multiorgan ($P = .01$) and central nervous...
system (CNS) conditions ($P < .01$) significantly increased over time. The neuromuscular disease group declined rapidly after the first 2 years of operation ($P = .01$), and has steadied since 2004. The proportion of deaths on program contributed by the chromosomal/multiorgan, cardio-pulmonary (both $P = .01$), CNS, and metabolic groups (both $P < .01$), significantly increased over time. During the study period, 390 children died. Age of death was normally distributed, averaging at 7.4 ($\pm 6.1$) years (Table 1). A survival curve of all children who had an opportunity to be on program for at least 2 years demonstrates that while half of the cohort dies within the first year on program, more than 40% is still alive 2 years later (Fig 1). Over time, the number of infants who died on our program significantly increased ($P < .01$), mirroring increases in perinatal and neonatal referrals.

The most prevalent EOL symptoms were dyspnea (41%), pain (22%), and problems with elimination (18%). Place of death was shared between hospice (61%), hospital (22%), and home (16%). Over time, the proportion of children who died at the hospice significantly increased ($P = .03$), whereas the proportion of home deaths decreased ($P = .01$). For in-hospice deaths transferred from hospital ($n = 152$), the length of stay for EOL care (12 $\pm$ 16 days) did not significantly differ from children who were admitted directly to hospice ($n = 61$; 4 $\pm$ 23 days; $P = .54$).

The annual contribution of diagnostic groups to the number of children on program does not necessarily mirror their contribution to mortality. Figure 2 depicts how this difference in contribution has changed over time (ie, proportion of deaths on program – proportion of children on program, per diagnostic group, per year). For example in 2010, cancers contributed 10% more to deaths on program than they did to children on program. Over time, these differences have become less extreme (significantly so for cancers at $P = .02$), speaking to changes in referral patterns and continuously refined acceptance criteria at intake.

The median number of days on program for all children was 301 (ie, at least 50% of children were on program for at least 10 months). Children with neuromuscular conditions stayed on program longer than other disease groups (median 2008 days). Children with cancer had shorter stays on program (median 60 days; another 25% survived to 150 days; Fig 3). Among children who died on program, 50% of deaths occurred in the first 2.5 months from time of acceptance. Median length of stay on program for children who transitioned and for children who were still alive at the end of the study was respectively 4.8 and 5.0 years.

Children are considered “accepted” onto the program regardless of whether their care will primarily occur in the hospice, in a hospital, or at home. This is distinct from an “admission,” which refers to a specific stay in the hospice. Detailed information on inpatient hospice admissions was only available from 2003 to 2010. Over this 8-year period, the number of total inpatient admissions did not significantly change. The number of respite admissions ($n = 2839$) decreased ($P = .08$), whereas the number of P&S ($n = 380$) and EOL admissions ($n = 140$) increased ($P = .01$ and $P < .01$, respectively). The neuromuscular group had the largest number of inpatient admissions. Children with cancer had a median of 1 admission (Fig 4).

Beginning in 2007, we recorded “reason for inpatient admission” separately from “reason for discharge,” because we found that a child may be admitted to the hospice for one reason with changing goals and events leading to a different discharge status. We have detailed discharge status for 362 children from 2007 to 2010. Over 4 years, the median and number of discharges per child were 3 and 7, respectively, with the majority of discharges being for respite ($n = 1026$), followed by P&S management ($n = 370$) and EOL care ($n = 85$).

Our experience with advance care planning, in the form of do not attempt resuscitation and modified intervention orders is being reported elsewhere. Critical symptom response (CSR) orders are part of the order set for EOL admissions. CSR orders are for high, rapidly given

### TABLE 1 Characteristics of All Children on the CPCH Program From 1996 to 2010

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boy</td>
<td>366</td>
<td>57.3%</td>
</tr>
<tr>
<td>Girl</td>
<td>276</td>
<td>42.7%</td>
</tr>
<tr>
<td>Home</td>
<td>56</td>
<td>16.4%</td>
</tr>
<tr>
<td>Hospice</td>
<td>207</td>
<td>60.7%</td>
</tr>
<tr>
<td>Hospital</td>
<td>74</td>
<td>21.7%</td>
</tr>
<tr>
<td>Other</td>
<td>4</td>
<td>1.2%</td>
</tr>
<tr>
<td>Gender</td>
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<tr>
<td>Other</td>
<td>4</td>
<td>1.2%</td>
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<tr>
<td>Diagnosis</td>
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</tr>
<tr>
<td>Cancer</td>
<td>194</td>
<td>30.2%</td>
</tr>
<tr>
<td>Cardio-pulmonary</td>
<td>40</td>
<td>6.2%</td>
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<tr>
<td>Chromosomal/multiorgan</td>
<td>67</td>
<td>10.5%</td>
</tr>
<tr>
<td>CNS</td>
<td>112</td>
<td>17.5%</td>
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<tr>
<td>Immunologic</td>
<td>12</td>
<td>1.9%</td>
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<tr>
<td>Metabolic</td>
<td>92</td>
<td>14.4%</td>
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<tr>
<td>Neuromuscular</td>
<td>124</td>
<td>19.3%</td>
</tr>
<tr>
<td>Entire cohort</td>
<td>390</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>174</td>
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</tr>
<tr>
<td>Cardio-pulmonary</td>
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<td>57</td>
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</tr>
<tr>
<td>Immunologic</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Metabolic</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Neuromuscular</td>
<td>31</td>
<td></td>
</tr>
<tr>
<td>Number of children who died in each diagnostic group: median, mean age of death in years (± SD)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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doses of analgesic, anxiolytic, sedative, or anticonvulsant medications. They are written for nurses to initiate in crises even before a physician can respond to a page. During our study period, CSR orders were written for 182 children, of which, 72 (40%) were implemented. Extubation or withdrawal of ventilator support was undertaken for 21 children. Of these, 2 survived for 3 weeks and 6 weeks, whereas another 2 survived over 1 year and eventually transitioned from the program.

Over 15 years, 97 children transitioned to adult health services. Of these, 51 were cognitively competent (30 with Duchenne muscular dystrophy, 3 “other” muscular dystrophies; 6 spinal muscular atrophies; 5 cancers; 3 HIV/AIDS; 2 cystic fibrosis; and 2 congenital cardiac diseases).

**DISCUSSION**

In this study, we describe the characteristics of infants, children, and youth ages 0 to 19 who received services offered by a freestanding palliative care hospice program with inpatient, in-hospital, and outpatient services from 1996 to 2010. Our primary aim was to better understand the characteristics of a matured pediatric palliative program, and describe elements of the population and services provided.

The number of children on our program has increased over time, which speaks to increased referrals and heightened...
involvement in the home and community. Although the number of respite discharges decreased over time (marginally significant), the number of total admissions remained steady, reflecting higher acuity levels and increased inpatient admissions for P&S and EOL care. Over time, the proportion of children dying at the hospice significantly increased, which may be in part a reflection of increased hospital transfers to the hospice for EOL care.

**FIGURE 3**
Number of days on CPCH program by diagnostic group (1996–2010). \(^{a}\) Calculated as date of acceptance to program through to either date of death/transition date/study end date. \(n\) = number of children in diagnostic category; \(m\) = median number of days on program.

**FIGURE 4**
Number of inpatient hospice admissions by diagnostic group at CPCH (1996–2010). \(n\) = total number of inpatient admissions in each diagnostic category; \(m\) = median number of inpatient admissions in each diagnostic category.
Patients with cancer had shorter median stays when compared with other diagnostic groups. This may reflect how families who have children with chronic, noncurable conditions opt to join the program early in the disease course to take advantage of opportunities available for respite, counseling, expressive and recreational therapies, and care coordination; whereas families whose child has cancer are invested in a cure-oriented approach and accept referral after curative options have been exhausted. Evolving partnerships between hospitals and hospices can facilitate an enhanced continuum of care for patients, allowing decisions around the most appropriate course of action, including the question of “the right place to die” and comfort care, to be best made.

Unlike adult palliative care, where nonmalignant diagnoses contribute to as few as 5% of inpatient hospice admissions and 23% of outpatient referrals, our findings demonstrate that the population of children served on a PPC program present with a wide variety of conditions. This is consistent with the findings of a multicenter study describing the clinical and demographic characteristics of patients seen by 6 North American palliative care teams, where 80.2% presented with noncancer diagnoses.

Length of stay on the CPCH program is a measure of survival from first date of acceptance. Feudtner et al found that the majority of pediatric patients with cancer were still alive 1 month after enrolment, and 69.7% of all patients were alive at 1 year. Although adults in palliative care survive an average of 1 to 3 months, 50% of the children on our program survived past 10 months. More than half of patients with cancer on our program survived past 2 months, with another quarter surviving past 5 months. For the overall cohort, two-thirds eventually die, yet 39% were still alive at the end of the study period. In examining patterns of care specific to the inpatient hospice unit, EOL constitutes a small fraction of admissions. These findings suggest that in this setting, palliative care is introduced relatively early in the child’s life so to engage in respite care and symptom management before EOL care is needed.

Advance care planning is a critical component of the PPC model, allowing the care team to align the needs and interests of the child with the goals and wishes of the family. Although the process is an on-going conversation, a related finding is the unpredictability of prognosis for children, even those admitted specifically for withdrawal of support. Although the majority of these children die quickly after support is removed, some remain alive for long periods of time. This experience has aided us in providing families with information on what to expect, specifically for ventilator withdrawal when many presume death will occur instantaneously.

Some populations are underrepresented in program review data. The majority of neonates die in hospital, with increasing consultation support from our team. The range of illnesses that fall under the umbrella of PPC (as described in Supplemental Appendix 1) now include a fifth category, perinatal palliative care. This is an area of noteworthy growth in our work, with significant increase in the last 3 years, which is not reflected in this retrospective review. CPCH has becoming increasingly involved in supporting these families with emotional preparedness regarding diagnosis, prognosis, treatment options, and psychosocial care. A detailed analysis of the mortality experience and palliative needs of infants who have been on the CPCH program has been published elsewhere. Children with cardiac diseases were also underrepresented in the CPCH cohort. During the time of our study, 236 deaths due to congenital heart disease alone occurred in the 0 to 18 population of the province; however, only 23 were cared for by CPCH. Reasons for understanding these inherent referral patterns need to be further explored with both clinicians and families.

Another emergent issue is the need for transition services. In our cohort, 15% moved on to adult care. Over half were cognitively competent and participated in their own transition planning. Young adults with special needs require support through this phase, as the province does not have a young adult hospice or palliative care team, a model that has been developed in the United Kingdom.

Transition involves coordination of numerous community services depending on the youth’s particular circumstances; a key object is reconnecting with a primary care practitioner (usually a family physician) for care coordination after transition.

We must acknowledge certain limitations within the study. We were restricted by the nature of a retrospective chart review with respect to data availability and completion. Further, because this study summarizes a palliative program in the province of British Columbia, it may not be transferable to other settings or models such as home-care programs. We do not have complete follow-up information for young adults who transitioned from our program with respect to the occurrence and circumstances surrounding death.

CONCLUSIONS

By conducting a 15-year retrospective review of the Canuck Place Children’s Hospice palliative care program, this review will ultimately help inform clinicians, staff, and other pediatric palliative hospice programs on the characteristics of and services provided to children living with and dying from LTCs. The program data provided in this report will be a first step toward evaluating the models of care used in
different settings, and help planners chose between models based on the characteristics and service needs of the population they predict to serve. An important step along this pathway will be the determination of agreed-upon processes and outcomes measures when comparing programs. Providing standard measurable outcomes is a challenge, as the population served presents with unique needs that are unlike those of other communities/health agencies. Reviews of PPC programs can provide models that can be used for new or existing programs when considering how delivery of care is to be proposed, improved, and/or expanded.

REFERENCES

Characteristics of a Pediatric Hospice Palliative Care Program Over 15 Years
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