

## Pediatric palliative care in Canada in 2012: a cross-sectional descriptive study

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### Abstract

**Background:** Pediatric palliative care focuses on comprehensive symptom management and enhancing quality of life for children with life-threatening conditions and their families. Our aim was to describe Canadian programs that provided specialized pediatric palliative care in 2012 and the children who received it and to estimate the proportion of children who might benefit that received specialized care.

**Methods:** A cross-sectional descriptive design was used. Specialized pediatric palliative care programs were included in the study if they offered multidisciplinary consulting pediatric palliative care services to a wide range of children and served all populations of children with life-threatening illness regardless of diagnosis. Investigators in programs that had taken part in a prior study were invited to participate. New programs that met the inclusion criteria were identified through snowball sampling within pediatric palliative care networks. Program data were obtained via surveys with coinvestigators, and health record reviews were used to obtain information about the children who received care through the programs.

**Results:** All 13 programs identified, including 3 with a free-standing hospice, agreed to take part in the study. Of the 1401 children who received care, 508 (36.2%) were under 1 year of age, and 504 (36.0%) had a congenital illness or condition originating in the perinatal period. Of the 431 children who died in 2012, 105 (24.4%) died in a critical care setting. Programs with a hospice provided care to 517 children (36.9%). Children in this group tended to be older, more often had a neurologic illness and received care for a longer time than those who received care from programs without a hospice. Overall, 18.6% (95% confidence interval 17.1%–20.3%) of deceased children who might have benefitted from specialized pediatric palliative care based on diagnosis received such care, with 110 (25.2%) receiving care for less than 8 days.

**Interpretation:** Program growth and changes in patients' demographic and clinical characteristics indicate improved reach of programs. However, barriers remain that prevent most children with life-threatening conditions from receiving specialized pediatric palliative care services.

Pediatric palliative care is an “active and total approach to care provided to children with life-threatening conditions and their families from the time of recognition or diagnosis of disease, throughout the illness, at the time of death and beyond. Pediatric palliative care includes management of symptoms, provision of respite, coordination of services, delivery of end-of-life care and provision of bereavement support.”<sup>1</sup> Although the principles of pediatric palliative care can and should be incorporated into care provided by any health care professional, there is increasing evidence suggesting that specialized programs may improve the quality of care for children and their families.<sup>2–6</sup>

In 2002, there were 8 pediatric palliative care programs in Canada, 7 based in pediatric tertiary hospitals and 1 free-

standing children's hospice. Clinicians from these programs conducted a study to describe program structures and populations served, and estimated that 5% of children who might benefit from specialized pediatric palliative care received care through one of the available programs.<sup>7</sup> Since the study was carried out, there has been steady growth in the availability of

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programs providing specialized pediatric palliative care to children with life-threatening conditions and their families.<sup>8</sup> Given the growth in the number of programs and wider availability of hospices, it is important to systematically document the current service structure, the population receiving care and the proportion of children who now receive care through these programs in order to plan programs and resources needed to provide high-quality care for these children.

We performed a study to describe the provision of pediatric palliative care in Canada in 2012. Specific research questions included: 1) What are the structures, processes and outcomes of care provided by specialist pediatric palliative care programs in Canada in 2012? 2) Are there significant differences in children's demographic and clinical characteristics (e.g., age, diagnosis), processes of care (e.g., time from referral to death, time from "do not resuscitate" order to death) or outcomes of care (e.g., location of death) when pediatric palliative care is provided through a hospice versus a hospital-based program? 3) What proportion of children who might benefit received care through a specialized pediatric palliative care program?

## Methods

We conducted a multicentre cross-sectional study, collecting data from multiple sources to compile a description of services and the population receiving them.

### Sample

Specialized pediatric palliative care programs were included in the study based on criteria used in 2002: offered multidisciplinary consulting pediatric palliative care services to a wide range of children and served all populations of children with life-threatening illness regardless of diagnosis. The programs were composed of professionals with expertise in both pediatrics and palliative care and were recognized regionally as being specialized pediatric palliative care programs with designated resources to provide this specific care.<sup>7</sup> The principal investigator (K.W.) contacted investigators in programs that had taken part in the 2002 study and invited them to participate. New programs that met the inclusion criteria were identified through snowball sampling within the Canadian Network of Palliative Care for Children and the Canadian Network of Pediatric Hospices; the resultant list was double-checked against the list of tertiary children's hospitals in Canada to ensure no programs were missed. All programs identified agreed to take part in the study. In cases in which the same core staff provided care at a free-standing hospice and in the associated hospital, this was counted as 1 program.

### Setting

A generalist level<sup>9</sup> of pediatric palliative care can be and is provided by health care professionals across Canada. However, for this study we were interested in the care provided through programs with pediatric palliative care specialists that fit our inclusion criteria, as these types of programs are linked to higher-quality care.<sup>2-6</sup> An important component of the setting of care in Canada is the availability of free-standing pediatric hospices, often associated with a children's hospital, that have been developed after the

model of hospices in the United Kingdom. In contrast to "hospice care" in the United States, a term typically denoting additional resources provided at the end of life, often in the home, Canadian pediatric hospices refer to physical buildings that provide respite care earlier in the patient's course along with specialized palliative care services throughout the patient's course.

### Data collection

Data were collected for all patients who received care through participating programs in 2012 (initial referral made during or before 2012 and child died in 2012 or was still alive and was being followed by the team at the end of 2012). The study data set was based on data collected in 2002 with an additional variable to indicate antenatal referrals, as this was raised as an emerging issue during the 2002 study (Appendix 1, available at [www.cmajopen.ca/content/4/4/E562/suppl/DC1](http://www.cmajopen.ca/content/4/4/E562/suppl/DC1)). Eligible patients were identified by the lead investigator at each site using clinical databases specific to the local program that included lists of all patients who had received care through the program. Any required data not available in the databases were collected through retrospective chart review conducted by the local investigator or a research assistant who received training from the principal investigator to ensure consistency across sites. All data were entered into the Research Electronic Data Capture database;<sup>10</sup> limits were set within the database to ensure that only data for eligible patients were entered.

We collected data about program structure and services via an email survey completed by the lead investigator at each program.

To estimate the proportion of children receiving specialized pediatric palliative care, we accessed vital statistics data from Statistics Canada on the population of children aged 19 years or younger and the total number and causes of childhood deaths in Canada during 2012.<sup>11</sup>

### Statistical analysis

We summarized the data descriptively using frequencies and proportions. We compared hospice and nonhospice programs using the  $\chi^2$  test (or Fisher exact test when the expected cell sizes were small). A *p* value of less than 0.05 was used to determine statistical significance. We used SPSS version 22 to conduct the analyses. Missing data were few and were included as an "unknown" category for each variable.

### Ethics approval

Research ethics board approval was obtained at each site before data collection.

## Results

### Pediatric palliative care programs

Thirteen programs met our inclusion criteria. Ten were based solely at tertiary hospitals, and 3 included a free-standing pediatric hospice. Table 1 lists the programs along with the start date, number of children who received care during 2012 and staffing. All programs functioned primarily in a consultative capacity but offered more front-line care at the end of life, particularly for managing challenging symptoms. Front-line care

was provided to children admitted to 1 of the 24 beds available across all hospices for respite, pain and symptom management or end-of-life care. An additional 11 beds were designated for end-of-life care in the hospitals, and 2 programs had pediatric palliative care outpatient clinics. Most core teams consisted of a physician and a nurse, with some bereavement coordinators, psychologists or social workers, for a total of 39.61 full-time-equivalent staff designated for provision of specialist pediatric palliative care in 2012 (Table 1).

### Pediatric palliative care patients

A total of 1401 children received specialized pediatric palliative care services in Canada in 2012 (Table 2). Included among the 1401 were 71 antenatal referrals (5.1%) for a fetus with severe anomalies. Of the 1401 children, 431 (30.8%) died during 2012, of whom 221 (51.3%) had received specialized care for less than 30 days and 110 (25.5%) for less than 1 week. Of the 970 patients who were still alive at the end of 2012, 543 (56.0%) had received specialized care for more than a year.

Programs with a free-standing pediatric hospice provided care to 517 patients (36.9%). There were statistically significant differences between children who received care through a program with an integrated hospice versus those who received care through one of the other programs (Table 2). Significantly fewer

children in the hospice-affiliated programs were younger than 1 year of age at the time of referral (160 [30.9%] v. 348 [39.4%],  $p < 0.01$ ), and significantly more had a disease of the nervous system (219 [42.4%] v. 156 [17.6%]), died in a hospice/palliative care bed (52 [41.9%] v. 14 [4.6%]) or received specialized pediatric palliative care for more than 1 year (293 [56.7%] v. 314 [35.5%]) ( $p < 0.001$ ).

Of the 105 children who died in a critical care setting, 48 (45.7%) were younger than 6 months of age at the time of death, and 28 (26.7%) were referred to pediatric palliative care a week or less before death. In addition, 23 (92.0%) of the 25 children whose condition was due to an external cause (e.g., attempted homicide, accident, complications of medical or surgical care) and who therefore might have been expected to die in a critical care setting were still alive at the end of the study period.

Across Canada, 3247 children aged 19 years or younger died from all causes in 2012. A total of 930 children died as a result of external causes, leaving 2317 children for whom pediatric palliative care may have been appropriate based on diagnosis. Of the 2317, 431 (18.6%, 95% confidence interval 17.1%–20.3%) received specialized pediatric palliative care. Recent and validated estimates of the prevalence of life-threatening conditions among children in Canada suggest that

**Table 1: Program staffing and number of children receiving care at programs offering specialized pediatric palliative care in Canada in 2012**

Program	Year program started	No. of patients	Staffing, FTE
<b>Programs including free-standing hospice*</b>			
Canuck Place Children's Hospice/BC Children's Hospital, Vancouver	1995	250	1.5 MD, 2.4 APN, 2.4 SW, 1.0 BC
Children's Hospital of Eastern Ontario/Roger's House, Ottawa	1999/2006†	170	2.0 MD, 1.0 APN, 1.0 RN, 0.8 SW
Alberta Children's Hospital/Rotary Flames House, Calgary	2001/2009†	97	3.4 MD, 0.8 APN, 0.8 SW, 0.8 BC
<b>Programs based at hospital</b>			
Hospital for Sick Children, Toronto	1986	326	2.16 MD, 2.0 APN, 1.8 BC
Centre hospitalier universitaire de Québec, Québec	2004	110	1.2 MD, 0.4 RN, 0.2 Psy
Winnipeg Regional Health Authority, Winnipeg	2006	97	1.0 MD, 1.0 APN
Centre hospitalier universitaire Sainte-Justine, Montréal	1999	67	0.5 MD, 2.0 APN, 0.8 Psy
IWK Health Centre, Halifax	1995	60	1.5 MD, 1.0 APN, 0.5 RN
Montréal Children's Hospital, Montréal	1992	57	0.9 MD, 0.5 APN
Stollery Children's Hospital, Edmonton	1999	54	1.05 MD, 0.8 RN, 0.8 BC
Children's Hospital London Health Sciences Centre, London, Ontario	2008	52	1.0 APN
Royal University Hospital, Saskatoon	2011	51	0.3 MD
Centre hospitalier universitaire de Sherbrooke, Sherbrooke, Quebec	2004	10	0.1 MD, 0.1 SW, 0.1 Psy
Total	–	1401	39.61 FTE

Note: APN = advanced practice nurse, BC = bereavement coordinator, FTE = full-time equivalent, MD = physician, Psy = psychologist, RN = registered nurse, SW = social worker.  
 \*Only "core staff" are listed. Additional staff (e.g., nurses, personal support workers) provide front-line care when children are admitted to the hospice.  
 †Hospital-based program started before the hospice; therefore, both dates are included.

**Table 2 (part 1 of 2): Patient demographic and clinical characteristics, processes of care and outcomes of care at programs with hospices versus other programs**

Variable	No. (%) of patients		
	Hospices	Other programs	Total
<b>All patients</b>	<i>n</i> = 517	<i>n</i> = 884	<i>n</i> = 1401
Age at referral, yr*			
< 1†	160 (30.9)	348 (39.4)	508 (36.2)
1–4	129 (25.0)	155 (17.5)	284 (20.3)
5–9	101 (19.5)	146 (16.5)	247 (17.6)
10–14	78 (15.1)	143 (16.2)	221 (15.8)
15–25‡	46 (8.9)	88 (10.0)	134 (9.6)
Unknown	3 (0.6)	4 (0.4)	7 (0.5)
Primary diagnosis§			
Congenital malformations, deformations and chromosomal abnormalities	124 (24.0)	278 (31.4)	402 (28.7)
Diseases of the nervous system	219 (42.4)	156 (17.6)	375 (26.8)
Neoplasms	66 (12.8)	155 (17.5)	221 (15.8)
Endocrine, nutritional and metabolic diseases	42 (8.1)	106 (12.0)	148 (10.6)
Conditions originating in prenatal period	25 (4.8)	77 (8.7)	102 (7.3)
Mental and behavioural disorders	12 (2.3)	14 (1.6)	26 (1.9)
Certain infectious and parasitic diseases	6 (1.2)	19 (2.1)	25 (1.8)
External causes of morbidity and mortality¶	6 (1.2)	19 (2.1)	25 (1.8)
Other	17 (3.3)	59 (6.7)	76 (5.4)
Unknown	0 (0)	1 (0.1)	1 (0.1)
<b>Patients alive at end of study period (Dec. 31, 2012)**</b>	<i>n</i> = 363	<i>n</i> = 574	<i>n</i> = 937
Time from referral to end of study period, d§			
≤ 30	31 (8.5)	75 (13.1)	106 (11.3)
31–90	9 (2.5)	53 (9.2)	62 (6.6)
91–180	22 (6.1)	57 (9.9)	79 (8.4)
181–365	40 (11.0)	107 (18.6)	147 (15.7)
> 365	261 (71.9)	282 (49.1)	543 (58.0)
<b>Deceased patients</b>	<i>n</i> = 124	<i>n</i> = 307	<i>n</i> = 431
Location of death§			
Critical care/emergency department	22 (17.7)	83 (27.0)	105 (24.4)
Home	21 (16.9)	71 (23.1)	92 (21.3)
General hospital unit	16 (12.9)	69 (22.5)	85 (19.7)
Hospice/palliative care bed	52 (41.9)	14 (4.6)	66 (15.3)
Labour and delivery unit	6 (4.8)	35 (11.4)	41 (9.5)
Community hospital	5 (4.0)	21 (6.8)	26 (6.0)
Other/unknown	2 (1.6)	14 (4.6)	16 (3.7)
Time from referral to death, d§			
≤ 1	7 (5.6)	42 (13.7)	49 (11.4)
2–7	12 (9.7)	49 (16.0)	61 (14.2)
8–30	28 (22.6)	83 (27.0)	111 (25.8)
31–90	22 (17.7)	46 (15.0)	68 (15.8)
91–180	13 (10.5)	29 (9.4)	42 (9.7)
181–365	9 (7.2)	23 (7.5)	32 (7.4)
> 365	32 (25.8)	32 (10.4)	64 (14.8)
Unknown	1 (0.8)	3 (1.0)	4 (0.9)

**Table 2 (part 2 of 2): Patient demographic and clinical characteristics, processes of care and outcomes of care at programs with hospices versus other programs**

Variable	No. (%) of patients		
	Hospices	Other programs	Total
Time from DNR order to death, d			
≤ 1	18 (14.5)	50 (16.3)	68 (15.8)
2–7	22 (17.7)	57 (18.6)	79 (18.3)
8–30	26 (21.0)	69 (22.5)	95 (22.0)
31–90	6 (4.8)	27 (8.8)	33 (7.6)
91–180	5 (4.0)	14 (4.6)	19 (4.4)
181–365	3 (2.4)	6 (2.0)	9 (2.1)
> 365	17 (13.7)	15 (4.9)	32 (7.4)
No DNR order	27 (21.8)	21 (6.8)	48 (11.1)
DNR status unknown	0 (0)	48 (15.6)	48 (11.1)

Note: DNR = do not resuscitate.  
<sup>\*</sup>*p* for comparison < 0.01.  
<sup>†</sup>Includes 71 antenatal consults, 25 in hospices and 46 in other programs.  
<sup>‡</sup>Six patients aged 20–25 years were included in the sample. They may have continued in pediatric care because of severe developmental disabilities or because death was considered to be imminent and a transfer to new care providers was seen as not being in the patient's best interests.  
<sup>§</sup>*p* for comparison < 0.001.  
<sup>¶</sup>E.g., attempted homicide, accident, complications of medical or surgical care.  
<sup>\*\*</sup>Patients transferred to adult care (*n* = 21) or discharged from palliative care (*n* = 12) were not included as their status on Dec. 31, 2012 was unknown.

9.8 out of every 10 000 children might benefit from pediatric palliative care services.<sup>12</sup> Based on a population of 7 826 123 children aged 19 years or younger,<sup>13</sup> the proportion who received specialized pediatric palliative care was 18.3% (95% confidence interval 17.4%–19.2%).

## Interpretation

The number of children who received specialized pediatric palliative care in Canada more than quadrupled between 2002 and 2012 (Appendix 2, available at [www.cmajopen.ca/content/4/4/E562/suppl/DC1](http://www.cmajopen.ca/content/4/4/E562/suppl/DC1)). However, most children (an estimated 81%) who might benefit are not receiving these services. As well, 51% of the children who died in 2012 received these services only for the last 30 days of their lives. Of the 16 children's hospitals in Canada, 13 (81%) now have a specialized pediatric palliative care program, whereas only 50% of children's hospitals in the US have such programs.<sup>14</sup> Although staffing has not kept pace with the increasing number of children receiving care, given the number of programs in Canada and the fact that 82% of surveyed pediatricians indicated they have access to pediatric palliative care,<sup>15</sup> the availability of programs does not appear to be the major barrier to receiving care in this country. Unfortunately, other barriers clearly remain that prevent full and timely use of specialized palliative services by the children who need them.

Compared to 2002,<sup>7</sup> lower proportions of children in 2012 had diseases of the nervous system (39.1% v. 26.8%) and malignant disorders (22.1% v. 15.8%), and a higher proportion had congenital conditions or conditions that originate in

the perinatal period (22.1% v. 36.0%). There were also differences in the location of death between the 2 cohorts, with a lower proportion dying at home in 2012 (43.9% v. 21.3%) and a higher proportion dying in a critical care (pediatric or neonatal intensive care) or emergency department setting (12.3% v. 24.4%). The increased proportion of deaths in critical care settings over time is in line with research indicating that most children die in hospitals, most often in critical care settings.<sup>16,17</sup> The change may reflect better integration of pediatric palliative care programs in these settings along with a change in culture, where palliative care is appropriately offered alongside continued attempts at life-sustaining therapies. However, referrals need to be made early enough for the team to have an impact on care. Just over a quarter of children who died in a critical care unit in 2012 met the pediatric palliative care team in the week preceding death. Children who died in critical care units primarily had chronic illnesses or conditions present from birth, and thus the possibility of death was likely evident much earlier. Delayed referral for these children raises concerns about the adequacy and timeliness of discussions about goals of care and whether families receive all the benefits associated with provision of expert pediatric palliative care.

Despite the prevalence of late referral, 60% of the children who received care through a program with a free-standing hospice in 2012 did so for over a year. The availability of respite care may be a deciding factor in parents' choosing to access a hospice,<sup>18</sup> which may explain the longer stays in these programs. The preponderance of older children and those with neurologic illnesses in hospice programs may also be linked to the availability of respite. Free-standing children's



hospices may offer a cost savings when patient-days in a hospice are compared with those in an acute care hospital.<sup>19</sup> However, construction and operating budgets are substantial and are often reliant on philanthropic funding, which raises questions about the sustainability of this model.<sup>20</sup> In areas where a pediatric hospice was available, 41.9% of children died in the hospice. This suggests that hospices may be an important alternative for families not comfortable being at home or where home care services are lacking.<sup>21,22</sup>

A higher proportion of children younger than 1 year of age at the time of referral received care in 2012 than in 2002 (36.2% v. 24.0%).<sup>7</sup> This proportion and the inclusion of antenatal referrals better represent the demographic features of childhood death: most children who die are younger than 1 year of age.<sup>11</sup> The notion of perinatal palliative care has emerged in the literature over the last decade.<sup>23</sup> Between 40% and 85% of parents choose to continue the pregnancy when a severe fetal anomaly is diagnosed,<sup>24–27</sup> and involvement of a pediatric palliative care program may be associated with less-aggressive interventions at birth.<sup>27</sup> Factors influencing the ability of programs to provide care to this emerging population include the location of the pediatric hospital in relation to obstetrical services at the adult hospital as well as logistical challenges around registration of an adult patient (the mother) in a pediatric hospital, even for outpatient consultations. The needs of the antenatal population fit with the principles of pediatric palliative care and represent an area of growth.

## Limitations

Study limitations include those inherent with collection of retrospective data via chart review, although some sites prospectively collected data following the 2002 study for their clinical records and did not require chart review as part of the current study. Estimates of children who might benefit from palliative care were quite crude; however, we used 2 different methods, 1 relying on cause of death recorded in the vital statistics and the other on population-based estimates of prevalence. The 2 methods resulted in similar proportions, which increases our confidence in the accuracy of the estimates.

## Conclusion

A fourfold increase in the number of children receiving specialized pediatric palliative care over a 10-year period is encouraging, but there is still work to be done in addressing barriers to ensure all children who might benefit from specialized pediatric palliative care have the opportunity to receive it. For children who do receive specialized pediatric palliative care, late referral raises questions about whether children and families are receiving the full benefits these services may offer.

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