ARTICLE

Pediatric Patients Receiving Palliative Care in Canada

Results of a Multicenter Review

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Objectives: To describe the patients who received care from the 8 dedicated pediatric palliative care programs in Canada in 2002 and to estimate the number of children who may have benefited but did not receive services from these programs.

Design: Retrospective review of medical records combined with a survey of each program.

Setting: Seven pediatric palliative care programs based in tertiary care settings and 1 freestanding children's hospice.

Participants: The programs cared for 317 children during 2002, of whom 123 died during that year. An additional 32 children died by the end of 2003.

Main Exposure: Pediatric palliative care program.

Results: Nearly half (48.6%) of the patients were younger than 5 years, and almost half of these were younger than 1 year. Primary diagnoses were disorders of the nervous system (39.1%), malignancies (22.1%), and conditions arising in the perinatal period or congenital anomalies (22.1%). Most of the children (43.9%) died at home, with those centers reporting more comprehensive home care services having the highest percentage of home deaths. From a national perspective, between 5% and 12% of the children who could benefit from palliative care received services from 1 of these programs.

Conclusions: Pediatric palliative care programs in Canada care for a diverse population of patients with a wide range of age and disease conditions. Only a small percentage of children who die, however, receive services from these dedicated programs.

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THE SENATE OF CANADA recently suggested that less than 15% of persons who could benefit from palliative care services in Canada actually receive them.[1] Recent studies in adults suggest that these numbers are increasing, but little is known about the number of children who receive palliative care in Canada.[2] Pediatric palliative care is becoming better established both as a mode of care for children living with life-limiting conditions and as a specialized medical discipline. There is evidence to suggest that pediatric palliative care services can improve quality of care and outcomes in these patients.[3]

While an increasing number of studies from single institutions report on pediatric deaths and the circumstances of these deaths,[3-12] to our knowledge, there is no published report examining pediatric palliative care services at a national level in any country. Absence of these data hampers the development of optimal health care policy. We, therefore, conducted a multicenter cross-sectional study to collect data that would provide an accurate description of Canadian children who received services from the 8 dedicated pediatric palliative care programs in Canada during 2002. We also estimated the number of children who may have benefited but did not receive care from one of these programs.

METHODS

SAMPLE

Programs

The following centers participated in the study: IWK Health Centre, Halifax, Nova Scotia; Sainte-Justine University Hospital, Montreal, Quebec; Montreal Children's Hospital, Montreal; Children's Hospital of Eastern Ontario, Ottawa; The Hospital for Sick Children (SickKids), Toronto, Ontario; Stollery Children's

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Hospital, Edmonton, Alberta; Alberta Children's Hospital, Calgary; and Canuck Place Children's Hospice, Vancouver, British Columbia. While some children may receive palliative care from individuals or on an ad hoc basis, at the time of the study, these 8 centers were the only pediatric palliative care programs in Canada that offered multidisciplinary, consulting pediatric palliative care services to a wide range of children and served all populations of children with life-limiting or life-threatening illness regardless of diagnosis. These 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. This study proposal was reviewed and approved by the health research ethics boards at each participating institution.

Patients

Patients were eligible for the study if they received care by one of the programs at any time in 2002.

DATA COLLECTION

Each site conducted retrospective reviews of medical records to obtain data about patients seen by their program in 2002. Data were reviewed from the time the patient was first seen by a member of the palliative care program (may have been first seen before 2002) until the patient died or until December 31, 2003, if the patient was still alive. Follow-up until December 31, 2003, allowed for a larger sample of deceased children for analysis of the circumstances of death. Data collected were based on an initiative by Health Canada to develop a national surveillance system for palliative care, which focused almost exclusively on adults. Data obtained from review of the medical records were as follows: sex, birth date, age, location of death, date of death, postal code, primary language spoken, race/ethnicity, primary diagnosis, date of formal primary diagnosis, other diagnoses, date of first referral to palliative care program, location at the time of referral, date of discharge or transfer (repeated as many times as needed to include all hospital/hospice stays), location to which discharged (repeated as many times as needed to include all hospital/hospice stays), date of "do not resuscitate" order, and cardiopulmonary resuscitation attempted at time of death (yes or no). The χ^2 test was used to explore differences between programs in age at time of referral, diagnosis, location at time of referral and at death, and time between referral and death. Statistics Canada data on deaths in children and total numbers of inpatient deaths at each participating center were obtained to allow for comparisons. In addition, 1 investigator (K.W., D.D., D.J.D., L.B., L.D., R.P.F., F.N., and M.R.) from each program involved in the study completed a survey to describe services they provide and the additional services that children and families may receive (ie, level of home care available to children in the community).

RESULTS

PROGRAMS

Seven programs were based in acute care hospitals and one was a freestanding children's hospice that operated independently but also provided consultation to a tertiary pediatric hospital. Most programs worked primarily on a consultant basis in hospital and home settings, providing substantial direct patient care in particularly difficult situations. Canuck Place Children's Hospice provided direct care to patients and families at the hospice. Although only 2 programs (Canuck Place Children's Hospice and Stollery Children's Hospital) had designated beds for end-of-life care, none of the investigators reported difficulty finding an inpatient bed for a child who needed end-of-life care. However, inpatient respite care was much more difficult to provide, with Canuck Place Children's Hospice being the only center providing this care on a consistent basis. Programs provided consultations in the home and made linkages with existing home care services. Home care services across Canada had highly variable levels, types, and hours of services available and variable levels of training for the home care nurses (usually trained in pediatric care or adult palliative care but rarely both).

The number of health professionals who provided care through these programs in 2002 is given in **Table 1**. Each program indicated the number of full-time equivalents paid through their program and other professionals they had access to in the health center during that time. These other health professionals were generally not trained specifically in pediatric palliative care but were available to provide some service. Most programs consisted primarily of a physician and nurse as the core team. While most centers reported that the team was available 24 hours a day, 7 days a week, for consultation and support for health professionals and families, the low number of dedicated full-time equivalents at each center leads one to question the sustainability of the service. Most centers indicated it was difficult to take breaks because there was no one to substitute for them when they were away.

PATIENTS

Of 317 children seen in 2002 by the 8 programs participating in the study, 155 died before December 31, 2003. In general, the population was fairly equal in terms of sex, and most patients were English speaking (outside of Quebec, where French is the primary language) and born in Canada. Most patients were very young; almost one fourth of the study group was referred for palliative care services before the age of 1 year and another fourth were aged 1 to 4 years at the time of referral (**Table 2**). This age demographic is similar to the number of children who die in Canada from all causes in a given year.[13] Children referred to Canuck Place Children's Hospice were significantly older than children referred to other centers ($P<.001$).

Diagnoses spanned a wide spectrum of disease processes (**Table 3**). Diseases of the nervous system (eg, Batten disease or leukodystrophy) accounted for 39.1% of the diagnoses, with combined malignancies (eg, leukemia, lymphoma, or sarcoma) accounting for another 22.1% of diagnoses. Conditions arising in the perinatal period (eg, extreme prematurity or birth asphyxia) combined with congenital anomalies (eg, trisomy 13 syndrome or Werdnig-Hoffmann disease) were the primary diagnoses in 22.1% of children. Significantly more children referred to Canuck Place Children's Hospice had a disease of the nervous system ($P<.001$). There was great variability across the country in terms of which disease grouping was referred to a palliative care program.

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Table 1. Full-time Equivalent Paid Positions in Each Program in 2002

Position	IWK	HSJ	MCH	CHEO	SickKids	Stollery	ACH	Canuck Place
Physician	1.0	*	0.8	*	. . .	0.5	0.2	1.0
Clinical nurse specialist	1.0	1.5	0.5	. . .	. . .	. . .	. . .	1.0
Nurse practitioner	. . .	. . .	. . .	. . .	1.0	*	. . .	. . .
Registered nurse	*	. . .	*	0.5	. . .	0.5	0.5	14.0†
Social worker	*	. . .	*	*	1.0	*	*	0.5
Bereavement coordinator	. . .	. . .	0.5	. . .	. . .	0.4	0.5	0.5
Spiritual care	*	*	*	*	*	*	*	0.5
Occupational therapist/physical therapist	*	. . .	*	*	. . .	*	*	*
Child life specialist	*	. . .	*	. . .	. . .	*	*	. . .
Volunteer coordinator	. . .	. . .	. . .	*	. . .	0.1	*	1.0
Music therapist	. . .	. . .	0.7	. . .	0.3	. . .	. . .	0.3
Psychologist/psychiatrist	*	0.8	*	*	. . .	*	*	. . .
Bioethicist	. . .	. . .	. . .	*	. . .	. . .	. . .	. . .
Recreational therapist	. . .	. . .	. . .	. . .	. . .	. . .	. . .	1.0
Pharmacist	*	. . .	. . .	. . .	. . .	. . .	. . .	. . .
School teacher/assistant	. . .	. . .	. . .	. . .	. . .	. . .	. . .	2.0
Nursing coordinator	. . .	. . .	. . .	. . .	. . .	. . .	. . .	1.0
Personal care aides	. . .	. . .	. . .	. . .	. . .	. . .	. . .	6.0
Intake nurse	. . .	. . .	. . .	. . .	. . .	. . .	. . .	0.5

Abbreviations: ACH, Alberta Children's Hospital, Calgary; Canuck Place, Canuck Place Children's Hospice, Vancouver, British Columbia; CHEO, Children's Hospital of Eastern Ontario, Ottawa; HSJ, Sainte-Justine University Hospital, Montreal, Quebec; IWK, IWK Health Centre, Halifax, Nova Scotia; MCH, Montreal Children's Hospital, Montreal; SickKids, The Hospital for Sick Children, Toronto, Ontario; Stollery, Stollery Children's Hospital, Edmonton, Alberta; ellipses, not applicable.

*Available in the health center, but no dedicated funding for pediatric palliative care.

†Includes both registered nurses and licensed practical nurses.

Table 2. Age at Referral in 317 Patients*

Age, y	Canuck Place	Other Centers Combined†	Total	Deaths in Canada, 2002
<1	9 (8.7)	67 (31.5)	**76** (24.0)	1762 (48.6)
1-4	29 (27.9)	49 (23.0)	**78** (24.6)	319 (8.8)
5-9	36 (34.6)	31 (14.6)	**67** (21.1)	231 (6.4)
10-14	23 (22.1)	31 (14.6)	**54** (17.0)	332 (9.2)
>15	7 (6.7)	35 (16.4)	**42** (13.2)	978 (27.0)

*Data are given as number (percentage) of patients; $P<.001$ using the χ^2 test for differences in the number of children in each age group between the Canuck Place Children's Hospice and the other centers combined.

†Includes data from IWK Health Centre, Halifax, Nova Scotia; Montreal Children's Hospital, Montreal, Quebec; Sainte-Justine University Hospital, Montreal; Children's Hospital of Eastern Ontario, Ottawa; The Hospital for Sick Children (SickKids), Toronto, Ontario; Stollery Children's Hospital, Edmonton, Alberta; and Alberta Children's Hospital, Calgary, because the numbers are too small to report by individual center and there was no statistically significant difference between these centers.

Location of care at time of consultation in 317 patients and at time of death in 155 patients is given in **Table 4**. Most referrals (45.7%) originated in general pediatric units at tertiary children's hospitals. An additional 10.1% of the referrals originated in an intensive care unit or emergency department. The palliative care team first saw 28.4% of the patients in their own home. At the time of death, more than one fourth (27.7%) of the children were hospitalized in a general pediatric unit in a tertiary children's hospital. An additional 12.3% died in a critical care area and 43.9% died at home. Only 7.7% of the children died in a hospice; however, at the time of the study there was only one pediatric hospice in Canada.

Time from first referral to the program until death (**Table 5**) was highly variable, from less than 1 day to longer than 1 year. With more than half of the study population alive at the time of data collection, 63.1% of the total sample were followed up by a pediatric palliative care program for longer than 1 year. Direct correlation between diagnosis and length of stay in the program from first referral to death was beyond the scope of this study; however, given the wide variation of diagnoses and attendant prognoses, this finding is not unexpected. Length of stay was significantly longer at Canuck Place Children's Hospice ($P<.001$).

Almost all of the children had a "do not resuscitate" order at the time of death. However, 10.3% did not have one until the day of their death and an additional 7.7% did not have one until the last week of their life (Table 5).

To compare the number of children who might benefit from a palliative care referral with the number who actually are referred, we determined the number of children who died in an inpatient unit in 2002 at each of the 7 participating hospitals that had a pediatric palliative care

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Table 3. Diagnoses in 317 Patients*

Diagnosis	Canuck Place	Other Centers Combined†	Total
Diseases of the nervous system	57 (54.8)	67 (31.5)	**124** (39.1)
Congenital illness or originating in perinatal period	12 (11.5)	58 (27.2)	**70** (22.1)
Malignancies	11 (10.6)	59 (27.7)	**70** (22.1)
Other illnesses	24 (23.1)	29 (13.6)	**53** (16.7)

*Data are given as number (percentage) of children; $P<.001$ using the χ^2 test for differences in the number of children in each disease category between the Canuck Place Children's Hospice and the other centers combined.

†Includes data from IWK Health Centre, Halifax, Nova Scotia; Montreal Children's Hospital, Montreal, Quebec; Sainte-Justine University Hospital, Montreal; Children's Hospital of Eastern Ontario, Ottawa; The Hospital for Sick Children (SickKids), Toronto, Ontario; Stollery Children's Hospital, Edmonton, Alberta; and Alberta Children's Hospital, Calgary, because the numbers are too small to report by individual center and there was no statistically significant difference between these centers.

Table 4. Location at Referral and Death for All Centers Combined*

Facility	Location at Referral	Location at Death
General unit in tertiary care center	145 (45.7)	43 (27.7)
Critical care area	32 (10.1)	19 (12.3)
Home	90 (28.4)	68 (43.9)
Hospice	0	12 (7.7)
Other	16 (5.1)	12 (7.8)
Unknown	34 (10.7)	1 (0.6)
Total	**317** (**100**)	**155** (**100**)

*Data are given as number (percentage) of children.

program. We then excluded those who died in the emergency department or within 24 hours of admission based on the assumption that a referral for palliative care may not have been appropriate for these children, given the short time from admission to death. In 2002, in the 7 hospitals included in the study, there were 428 inpatient deaths, excluding those that occurred in the emergency department or within 24 hours of admission. Of those 428 children, only 50 (11.7%) were seen by one of the pediatric palliative care programs.

Data from Statistics Canada were obtained on the total number of children who died and the cause of death during 2002. Of the 3622 children 19 years old or younger who died of all causes, 1148 died as a result of external causes such as transport accidents, falls, drowning, poisoning, assault, and complications of medical and surgical care.[13] Only 123 Canadian children who died in 2002 received specialized palliative care services. Therefore, even when children who died of causes that may preclude a referral to palliative care are excluded, the referral rate to pediatric palliative care programs in Canada was 5%.

It is difficult to determine how many children could benefit from palliative care at any given time. Data from

Table 5. Time From Initial Referral to Death and From DNR to Death for All Centers Combined*

Time, d	Referral to Death	DNR to Death
0-1	11 (7.1)	16 (10.3)
2-7	15 (9.7)	12 (7.7)
8-30	23 (14.8)	30 (19.4)
31-90	28 (18.1)	26 (16.8)
91-180	11 (7.1)	10 (6.5)
181-365	29 (18.7)	15 (9.7)
>365	38 (24.5)	27 (17.4)
DNR order present but timing unknown	. . .	12 (7.7)
No DNR order	. . .	7 (4.5)
Total	**155** (**100**)	**155** (**100**)

Abbreviations: DNR, "do not resuscitate"; ellipses, not applicable.
*Data are given as number (percentage) of children.

the Institute of Medicine in the United States estimate that on any given day 8600 US children would benefit from palliative care services because of limited life expectancy and seriousness of need.[14] Similar data from the United Kingdom estimate that for every 50 000 living children, 25 will require active palliative care at any one time.[15] Applying the estimates from the United Kingdom to the Canadian 2001 census data on the number of children 19 or younger living in Canada,[16] as many as 3889 children in Canada could benefit from involvement with a pediatric palliative care service annually. During 2002, only 317 (8.2%) of these actually had contact with a formal service.

COMMENT

The major finding of this study is the small percentage of children who receive care from a pediatric palliative care program in Canada. We used 3 methods to estimate the number of children who might benefit from contact with a pediatric palliative care program and who had contact with one of the centers in the study during 2002. We estimate that between 5% and 12% of Canadian children who might benefit from services from a pediatric palliative care program received these services. Each of the programs in this study provide care in wide geographic areas, sometimes via telephone consultation; however, there remain large areas of the country in which children do not have access to a formal pediatric palliative care program. In the survey of the 8 programs, referrals that are not made or are made too late were identified as other barriers to the provision of quality palliative care. Reasons for this were not examined in this study. However, other studies have reported great difficulty in identifying children who would benefit from palliative care services even when there is awareness by the primary health care team that the child has a fatal illness and there is no further curative therapy available.[17-19]

There were obvious differences in referral patterns among centers. For example, children who had malignancies represented as much as 40% of the patients seen by some programs, while other programs received no re-

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ferrals for children with a malignancy. Such discrepancies warrant further research but likely reflect referring physician preference for involvement with a palliative care program rather than patient variation relating to diagnosis or preferences among centers.

The main purpose of this study was to accurately depict demographic data about Canadian children who receive palliative care services from professionals with pediatric palliative care expertise. Most of the children (43.9%) died at home, perhaps mirroring the desire of Canadian adults to die at home.[20] There was great variability across the country in the percentage of children within each program who died at home (18%-86%) compared with in hospital. Home care services were accessible in all cities in which the pediatric palliative care programs were based; however, there was great variability in the training of home care staff and availability of services. The centers that reported having more comprehensive home care programs, including consistent and prompt access 24 hours a day, 7 days a week, and specific training in pediatric palliative care, had significantly more home deaths, perhaps implying that availability of better home care services allows more families to take advantage of this option. When families are not well supported to care for their sometimes highly symptomatic children at home, hospitalization is likely the default option even if this is inconsistent with patient or family wishes. This surveillance study suggests that further research is warranted to evaluate the relationship between comprehensiveness of children's home care and palliative care services and the percentage of families who opt for a home death.

The diverse nature of the patients in terms of age, diagnosis, and duration of survival is markedly different from most adult palliative care programs in Canada, which mainly serve symptomatic patients with advanced cancer for a relatively short length of stay.[2] This discrepancy may be explained by the evolution of many adult palliative care programs from a cancer-care model, whereas the programs described in this study evolved from a family-centered child health model. Patients from Canuck Place Children's Hospice had a significantly higher percentage of nervous system diseases in addition to being an older group of patients. However, the broad spectrum of disease infers variable trajectories of illness before death and the need for individualized approaches through multidisciplinary care. In addition, health professionals must be able to revisit issues as the disease progresses or changes and as the child's developmental needs and level of understanding change.

This study was limited in that it was retrospective. In addition, data were obtained by multiple persons at multiple sites, perhaps reducing consistency of data obtained. Another potential confounder is that Canuck Place Children's Hospice was the only freestanding children's hospice at the time of study. Although 1 of 8 study centers, it contributed almost one third of the patient study population. This population was significantly different from the other programs based in tertiary children's hospitals (older age, preponderance of nervous system disorders, and longer length of stay), which may reduce the generalizability of the findings.

CONCLUSIONS

Research about care at the end of life is difficult, and this is compounded when the study population is dying children. This study is important because, to our knowledge, it reflects the first attempt to describe on a national level the demographic features of children who are receiving available palliative care services. However, because of its retrospective design, it leaves unanswered questions about the quality and type of care provided and how it may differ from the care delivered by those without pediatric palliative care expertise. Despite these limitations, this study begins to identify these children as a distinct population requiring specialized health services and to reveal who these children are. Future surveillance studies should include information on ages of siblings, race/ethnicity and spoken language of parents, and number of consultations specifically for bereavement follow-up. Further research directions from this study include case-control studies of children and families who receive specialized pediatric palliative care services compared with those who do not. Such endeavors would allow a better description of the perceived quality of end-of-life care relative to various palliative care delivery models. Outcomes to be evaluated include relief of pain and other symptoms, ability to remain in a setting of the family's or patient's choosing, ability to achieve personal and family goals throughout the child's illness, and satisfaction of parents with services both during their child's illness and after the child's death.

This surveillance project reveals that most Canadian children who may benefit are not referred to existing pediatric palliative care services or do not have access to services because of geographic availability. This deficiency may be used to inform policy makers in children's hospitals and local health regions to rethink current methods of referral, with the aim of making more accessible these services and programs to families that may benefit from them but of which they remain unaware. In addition, development of more programs including hospices and comprehensive home care systems across Canada may offer children and families more choice about the setting in which they receive palliative and end-of-life care. As the title of the 2000 Senate of Canada report[21] indicates, quality end-of-life care is the right of every Canadian. This right extends particularly to one of our most vulnerable populations, our children.

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A smart mother makes often a better diagnosis than a poor doctor.
—August Bier, German professor of surgery, 1861-1949

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