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A paediatric palliative care programme in development: trends in referral and location of death

C M Vadeboncoeur,^{1,2} W M Splinter,^{1,3} M Rattray,¹ D L Johnston,⁴ L Coulombe^{1,2}

¹Pediatric Palliative Care Outreach Team, Children's Hospital of Eastern Ontario, Ottawa, Ontario, Canada

²Department of Pediatrics, University of Ottawa, Ottawa, Ontario, Canada

³Department of Anesthesiology, University of Ottawa, Ottawa, Ontario, Canada

⁴Division of Hematology/Oncology, Department of Pediatrics, Children's Hospital of Eastern Ontario, University of Ottawa, Ottawa, Ontario, Canada

Correspondence to

Christina M Vadeboncoeur, Pediatric Palliative Care Outreach Team, Children's Hospital of Eastern Ontario, Ottawa, ON K1H 8L2, Canada; vadeboncoeur@cheo.on.ca

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ABSTRACT

Purpose To describe the formation of a paediatric palliative care programme providing care in hospital, at home or in hospice, ensuring continuity of care where the child and family desire.

Study design Descriptive analysis was performed on referral source, diagnosis and reason for discharge for patients referred to the Palliative Care Team at the Children's Hospital of Eastern Ontario in Ottawa, Ontario, Canada from 1999 to 2007.

Results 341 children were referred. 24% had a neurological condition, 21% had genetic disorders or congenital anomalies, 20% had cancer, 18% had metabolic or neurodegenerative conditions and 17% had another diagnosis. The major sources of referral included paediatricians, neonatologists, oncologists and intensivists. 55% of the children have died. 58% of these died in hospital, 27% at home and 15% in hospice. Of the remaining 152 children, 7% were discharged from the programme after clinical improvement, 4% were moved to another geographic location or an adult centre, 2% were not eligible, 1% declined services and 4% were lost to follow-up. The remaining 90 children continue to be followed-up. In the hospitalised patients who died, the annual referral rate increased from 20% to >50%.

Implications Referral to the palliative care team has increased over time in all diagnostic categories and from all sources. Most children died in hospital; however, a significant number of families chose end-of-life care at home or in a hospice.

Palliative care is a relatively new discipline in paediatrics. The goal is to care for children and youth with life-threatening and life-limiting illnesses. Attention is focused on physical, emotional, social and spiritual elements.¹ This symptom-based care is provided in a variety of contexts, including support during hospitalisation, outreach while at home, respite and end-of-life care. Unlike the case in adult medicine, children with cancer comprise less than one third of the referrals to paediatric palliative care. Most referrals are from physicians caring for children with neurodegenerative conditions, metabolic defects, rare genetic conditions, congenital anomalies or catastrophic illnesses.²⁻⁴

Many institutions have developed palliative care services based on the local resources and expertise available, which have resulted in many different models of care.⁵⁻¹¹ Before 1999, children in our tertiary care paediatric hospital received end-of-life care from individual services. Some children and families asked to be at home for end-of-life care, but most of our primary care physicians, including paediatricians, family doctors and adult palliative care physicians, did not provide this type of care. It was, therefore, initially

What is already known on this topic

- ▶ Current medical technology and practice is allowing children with complex, life-limiting medical conditions to survive, and these children benefit from coordinated care including palliative care support in medical decision making.
- ▶ Many of these families are choosing end-of-life care out of hospital settings.

What this study adds

- ▶ Description of a successful coordinated model of care in hospital, home or hospice according to family wishes, augmenting the existing medical team.
- ▶ Model that can be used for new or existing programmes when considering how delivery of care is to be proposed or expanded.

provided by a family physician experienced in home-based palliative care; however, the demand for this type of care was unable to be met by one individual. Thus, at our hospital, a need for coordinated palliative care services was identified in the 1990s. A palliative care nursing coordinator position was created in 1999. At that time, there were a number of people including physicians and allied health staff available to the coordinator but none with time dedicated to palliative care. The service evolved into an outreach palliative care team in late 2003 and comprised members from a variety of disciplines, which now include nursing (1999), bioethics (1999), pharmacy (1999), physician (2003), social work (2003) and child life (2006). This team works in conjunction with the child's primary and subspecialty healthcare professionals to provide a coordinated plan of care at the location desired by the child and the family. A bequest for paediatric palliative care allowed the construction and opening in 2006 of a paediatric hospice in our area to assist in provision of care to children and their families followed-up by our service either during the transition from hospital to home, as respite care or as end-of-life care.

Our paediatric palliative care outreach programme asked two questions that formed the basis of this study. The first was how patterns of referral to a palliative care team evolved after the formation of the outreach team and after the paediatric hospice became available. The second was whether

end-of-life care could be provided by the team in the hospital, in the hospice or in the home setting.

METHODS

Data were collected on all the patients referred to the palliative care team at the Children's Hospital of Eastern Ontario (CHEO) between 1999 and 2007. CHEO is a tertiary care paediatric institution, serving a population of approximately 500 000 children and youth in Eastern Ontario, Western Quebec and Baffin Island, Nunavut. Records kept by individual team members and in a central palliative care database were reviewed to collect referral source, diagnosis and reason for discharge from the service. The individual team members' records used included those of the palliative care coordinator and the palliative care team physicians. A descriptive analysis was performed on all the data.

RESULTS

During the study period, 341 children were referred to the palliative care team. The distribution of referral diagnosis showed that 24% of the children were referred for neurological conditions; 21%, for genetic disorders or congenital anomalies; 20%, for cancer; 18%, for metabolic or neurodegenerative conditions and 17% for other diagnoses (table 1). There is an increase in referrals from all the diagnostic categories over the study period.

Over the 9-year period studied, the sources of referral included general paediatrics (25%), neonatology (18%), paediatric oncology (18%), paediatric intensive care (16%) and paediatric neurology (9%) with 14% coming from other sources (table 2). Referrals from all the groups showed an increasing trend over time. There is, in particular, an increase in referrals from the neurology and the paediatric and neonatal intensive care units since the opening of the paediatric hospice in 2006.

The outcome of the 341 children referred shows that 189 (55%) have died. Twenty-three children (7%) met the palliative care criteria for a period and then were discharged from the programme. These were children who were either referred for pain and symptom management or who experienced catastrophic illness from which they recovered. Fourteen patients (4%) were transferred either to another geographic location or to an adult centre. Eight children (2%) were judged not to have progressive life-limiting illness at the time of referral and thus were not eligible for palliative care services. Five children (1%) were from families who declined palliative care services. Twelve children (4%) referred to the service have been lost to follow-up. The remaining 90 children (26%) continue to be in contact with the team.

Table 3 shows the data on the location of death for the children referred to the service. Of the 189 children who died, 110 (58%) died in hospital, 51 (27%) died at home, 26 (14%) died in paediatric hospice and 2 (1%) died in adult hospice. The authors are aware of two children who were discharged home to die without referral made to the palliative care team. Both of these were neonates with severe cardiac disorders who were discharged to the care of their family doctor in another province. The authors are not aware of any other patients expected to die who were discharged from hospital without the team involved.

The expansion of the palliative care coordinator position to a multidisciplinary outreach paediatric palliative care team and the opening of a paediatric hospice in our area have led to an increase in referrals to the palliative care service. The number of deaths occurring at home has remained steady over the years examined (table 3); however, both the number of deaths in hospital in which the palliative care team was involved and the proportion of out-of-hospital deaths has increased over time.

Table 1 Referral diagnosis by year

Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	Total
Neurological	4 (25)	8 (28)	8 (31)	6 (20)	10 (36)	11 (28)	7 (19)	16(24)	13 (19)	83 (24)
Genetic or congenital anomalies	5 (31)	2 (7)	5 (19)	7 (23)	6 (21)	2 (5)	13 (36)	17 (25)	16 (23)	73 (21)
Cancer	1 (6)	6 (21)	4 (15)	9 (30)	4 (14)	11 (28)	4 (11)	13 (19)	15 (22)	67 (20)
Metabolic or neurodegenerative	2 (13)	4 (14)	5 (19)	4 (13)	6 (21)	12 (30)	4 (11)	12 (18)	11 (16)	60 (18)
Other	4 (25)	9 (31)	4 (15)	4 (13)	2 (7)	4 (10)	8 (22)	9 (13)	14 (20)	58 (17)
Total	16	29	26	30	28	40	36	67	69	341

The data are expressed as number of patients (per cent of total).

Table 2 Source of referral by year

Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	Total
General paediatrics	5 (31)	7 (24)	11 (42)	9 (30)	10 (36)	15 (37)	11 (31)	7 (10)	10 (14)	85 (25)
Neonatology	5 (31)	8 (28)	3 (12)	5 (17)	2 (7)	3 (7)	7 (19)	14 (21)	15 (22)	62 (18)
Oncology	1 (6)	5 (17)	4 (15)	9 (30)	4 (14)	10 (25)	4 (11)	11 (16)	12 (17)	60 (18)
Intensive care	4 (25)	5 (17)	6 (23)	1 (3)	4 (14)	2 (5)	8 (22)	10 (15)	13 (19)	53 (16)
Neurology	0	2 (7)	1 (4)	1 (3)	3 (11)	2 (5)	0	14 (20)	9 (13)	32 (9)
Other	1 (6)	2 (7)	1 (4)	5 (17)	5 (18)	8 (20)	6 (17)	11 (16)	10 (14)	49 (14)
Total	16	29	26	30	28	40	36	67	69	341

The data are expressed as number of patients (per cent of total).

Table 3 Location of death by year of patients referred to palliative care

Year	1999	2000	2001	2002	2003	2004	2005	2006	2007	Total
Hospital	10 (77)	17 (81)	9 (53)	13 (62)	7 (54)	16 (70)	14 (78)	14 (48)	10 (29)	110 (58)
Home	3 (23)	4 (19)	7 (41)	7 (33)	6 (46)	7 (30)	4 (22)	6 (21)	7 (21)	51 (27)
Hospice	0	0	1 (6)	1 (5)	0	0	0	9 (31)	17 (50)	28 (15)
Total	13	21	17	21	13	23	18	29	34	189

The data are expressed as number of patients (per cent of total).

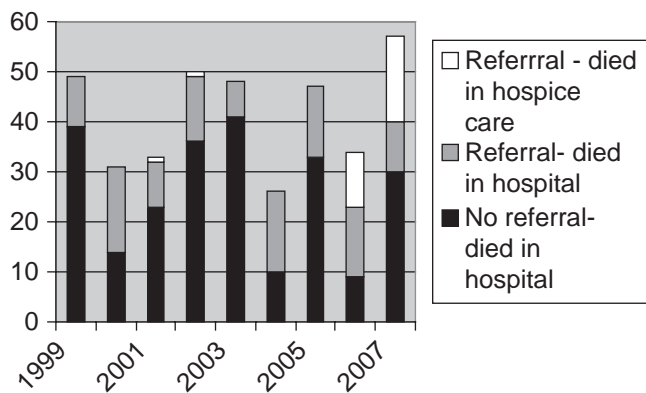


Figure 1 Total deaths of hospitalised children. Total deaths of hospitalised children showing those who died in the hospice, in the hospital with palliative care involvement and in the hospital without palliative care involvement.

The number of patients who died in hospital who were referred to the palliative care service before death was examined. Before 2003, when a palliative care physician became identified as part of the team, only 20%–30% of patients dying in hospital were referred to palliative care. Rates of referral increased after 2003 and then again after the hospice opened in 2006. Since the opening of the paediatric hospice in May of 2006, the proportion of hospitalised children who died and were referred to the palliative care team increased to >50%. The children who died in the paediatric hospice were referred while in hospital and have been included because they are deaths that would likely have otherwise occurred in hospital (fig 1).

INTERPRETATION

Our centre, like the paediatric community in general, is recognising that palliative care is an important aspect of paediatric medicine that aims to relieve the symptoms and suffering of children and families living with life-limiting diseases. A coordinated paediatric palliative care programme can provide care to these children and provide end-of-life care in hospital, at home or in a hospice setting. As the resources of our programme grew and became better known, the number of referrals increased. Children were referred to the programme for a variety of diagnoses and by many sources. We found an increase in referrals as the team expanded in 2003 to include identified social work resources and a physician experienced in palliative care that was available for all patients. There was a second increase after the opening of the paediatric hospice in May of 2006. Some of the latter referrals were a means to accessing respite care for patients with high medical needs as stated on the referral forms. Data from each period were compared to determine if referral patterns were also affected. The data distribution for referral diagnosis is similar in each period to the overall distribution, with a modest relative increase in referral for neurological diagnoses since the opening of the hospice. The source of referral was similarly examined, and there was an increase in referrals from the intensive care units (both paediatric and neonatal) and from the neurology service after the opening of the hospice. The increase in referrals after identified social work and physician resources became available is explained by the recognition of expertise in palliative care increasing confidence in pain and symptom management of children referred. The increase in referrals after the opening of the hospice reflects two facts. First, the increase in referrals from the intensive care setting

shows the desire of some families for end-of-life care outside of the hospital setting, particularly in cases where care at home may not be possible. Second, the increase in referrals from the neurology service demonstrates a need for respite care for children and youth with high medical needs. The authors are not aware of other published data that looks specifically at referral patterns in paediatric palliative care.

A recent study by Feudtner *et al*¹² examined the location of death in children with complex chronic conditions. Using a national database in the USA from 1989 to 2003, they showed an increasing trend to dying at home. The number of families followed-up by our team who cared for their child at home during the final phase of their illness ranged from 3 to 7 and remained rather constant over the study period; thus, we did not show the same trend. One reason for this difference may be that our number of patients and shorter study period do not allow such a trend to be evident. Another possible explanation is that support for provision of end-of-life care at home has been available to our patient population since our data collection began.

Most children who died did so in hospital; however, there were a consistent number of families who requested and were able to care for their children at home during their final hours and days. The building of a paediatric hospice allowed families a third choice of location to care for their child during this difficult time. The hospice is located on the hospital grounds; therefore, allowing the provision of hospice-based end-of-life care on a rapid basis when desired. In our centre, the options of care at home and in the hospice are limited by geography as our paediatric hospital cares for children and families from a large area and from other provinces and territories. Arrangements for care at home need to be coordinated with local health resources in the area where the family resides. The hospice itself is limited to residents of Ontario.

This study is purely descriptive and does not address all of the factors that would influence decisions about whether or not to refer children to a palliative care service. Neither does it address any elements of patient or care giver satisfaction with palliative care services. It does, however, illustrate how paediatric palliative care can be delivered in a coordinated manner in a location agreed upon by the patient, family and care givers. The challenges of caring for children from other provinces and attempting to provide equal access to care are beyond the scope of this discussion.

Support for the benefits of palliative care is starting to appear in the paediatric literature. Wolfe *et al*¹³ used a parent survey for families who had lost a child to cancer. Two groups were surveyed before and after institution of an interdisciplinary palliative care team to improve communication, symptom control and quality of life. The parents in the latter group reported decreased pain and dyspnoea in their child during end-of-life care and felt more prepared during the child's last month of life and during their death.¹³ More studies are needed in paediatric populations using standardised interventions to build evidence to support the benefit such programmes offer.

In conclusion, as time has allowed familiarity with the paediatric palliative care programme in our centre and with the growth in both human and material resources, the rate of referral has increased. This has allowed care for more children with life-limiting and life-threatening illnesses and additional support for their families. Our aims at the current time are to continue to encourage timely consultation of children who are eligible for our programme, to target populations who are eligible for services but are seldom referred and to continue to educate hospital personnel and patient populations about the services we have to offer. We also hope to build on the evidence that support the benefits of paediatric palliative care.

Competing interests None.

Ethics approval Ethics approval was given by the CHEO Research Ethics Board.

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