

A report on location of death in paediatric palliative care between home, hospice and hospital

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This retrospective study analysed data for 703 children who died from 2000 to 2006 to examine where children with a broad range of progressive, life-limiting illnesses actually die when families are able to access hospital, paediatric hospice facility and care at home. There was an overall even distribution for location of death in which 35.1% of children died at home, 32.1% died in a paediatric hospice facility, 31.9% in hospital and 0.9% at another location. Previous research suggests a preference for home as the location of death, but these studies have primarily focused on adults, children with cancer or settings without paediatric hospice facilities available as an option. Our results suggest that the choice of families for end-of-life care is equally divided amongst all three options. Given the increasing numbers of children's hospices worldwide, these findings are important for clinicians, care managers and researchers who plan, provide and evaluate the care of children with life-limiting illness. *Palliative Medicine* (2008); 22: 831–834

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Introduction

With recent advancements in paediatric palliative care and an increase in the number of dedicated paediatric hospices, research into location of death needs to be updated. When a child dies, the place of death may have important implications for families' experience of death and subsequent bereavement, although it may not be the sole factor impacting this experience. Lower levels of grief-related symptoms and psychological distress have been reported for families whose child died at home.^{1,2} Location of death may also influence care delivery; for example, children are more likely to have a do-not-resuscitate (DNR) order when they are on a hospice programme.³ Now that the field of paediatric palliative care has grown, with somewhere between 40 and 60 paediatric hospices operating globally and many more hospital and community-based paediatric palliative care teams, it is necessary to re-examine where children actually die when families have access to hospital, paediatric hospice and care at home.

The commonly accepted view is that most patients at end-of-life prefer to die at home. Much of the research supporting this view comes from studies undertaken in adults.⁴ Recent paediatric research also suggests that parents and children with progressive, life-limiting conditions

(cancer and non-cancer) state a preference for home as the location of death.⁵ The limited paediatric literature, however, focuses on cancer diagnoses, on parents' stated wishes and on research undertaken in settings where no paediatric hospices existed.^{6,7} Factors that often influence this decision include specific diagnosis, age of the child, local area affluence and location of home.⁸

A stated preference for location of death is not the same as actual location of death. Goldman, *et al.*⁹ reported on location of death for children with cancer in the United Kingdom for the period 1987–1988. At that time, there were only three operational paediatric hospices, and only one of the 37 deaths reported in that study occurred in a children's hospice. Subsequently, in a study of children who died from cancer between 1995–1999 in England and Wales, the majority (52.2%) died at home, whereas 43.3% died in the hospital and only 3.1% in the hospice.⁶ A recent study by Vickers, *et al.*⁵ followed children in 22 oncology centres in the United Kingdom. They found that many families state a preference for home deaths and that a large percentage of paediatric oncology patients are indeed able to have a home death when key programme components, such as a paediatric oncology outreach nurse specialist with physician support, are available. In settings without a paediatric hospice, availability of a palliative care unit in hospital may actually have a different impact and decrease the numbers of home deaths.¹⁰

There are few equivalent studies of children with non-cancer diagnoses. A recent study by Feudtner, *et al.*¹¹

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analyzing the place of death of children with complex chronic conditions who died in the United States from 1989–2003 showed that the percentage of children dying at home, in comparison to the hospital, had significantly increased. Feudtner and Leuthner, *et al.* have shown that children with complex chronic conditions and infants with progressive, life-limiting conditions continue to have higher rates of hospital-based deaths, but otherwise there has not been substantial examination of where children with non-cancer diagnoses die or how families make decisions about location of anticipated death.^{7,8}

Current options for children, depending on local resources, may include one or more of the following: a palliative service within a children's hospital, a paediatric hospice facility located in geographic proximity to the family or the availability of an experienced team ready to provide care in the home. To best meet the needs of families caring for children at the end of life, there may need to be several programme options available. When all three options are present, families may be able to choose to move between hospital, hospice and home with minimal barriers, as their needs change.

We sought to describe the location of death of children with a broad range of progressive, life-limiting conditions (both cancer and non-cancer) who died under the care of a paediatric palliative care team and at the time of death had equal access to paediatric palliative care in home, hospital and paediatric hospice facility. Unlike recent studies that examined place of death for those whose options include only at home or hospital for paediatric patients, our study examined the location of death when a third option, a paediatric hospice facility, was also available at the same time.

Methods

Data source

We conducted a retrospective case series of all paediatric patients who were cared for by three paediatric palliative care programmes and who died between 2000 and 2006. Each of the programmes was associated with a well-established (greater than 10 years of operation) specialist paediatric hospice facility, a tertiary care children's hospital and community-based teams in one of three countries: Australia, Canada or the United Kingdom. These programmes provide direct and/or consultative service at the children's hospice facility, at a nearby tertiary care children's hospitals and to community palliative teams. A child referred to any of the three programmes described in this report is followed from the time of acceptance, regardless of whether death occurs in hospice, hospital or home.

Furthermore, collaboration amongst the various institutions and teams in each setting enables smooth transitions for families. Families had the opportunity to move

back and forth between settings, for example, they may have chosen home for end-of-life care initially but later opted to move to a hospice. In our clinical experience, some families made more than one such move as their situation changed or as they discovered what worked best for them. Because of the nature of the health care systems in each of the countries included in this report, cost was not a barrier to families' access.

The Children's Hospital at Westmead, Sydney, Australia operates an integrated system of paediatric palliative care which offers care at home, in-hospital or in the six-bed children's hospice facility, which opened in 2001 (Bear Cottage, Manly).^a Canuck Place Children's Hospice is located in Vancouver, Canada, and the hospice facility has nine beds. The Canuck Place programme has a close affiliation with BC Children's Hospital, providing direct service there. The programme also provides consultation support to the community-based palliative teams across the province of British Columbia and the Yukon Territory via 24 h/day physician and nurse consultation coverage. Martin House Children's Hospice opened in the United Kingdom in 1987, initially with nine beds. A further six beds for teenagers and young adult were added in 2001. For the period of this study, the catchment area was East, West and North Yorkshire. The Martin House consultant paediatrician has close links to the Leeds Teaching Hospitals. Family-led care is provided with support to local community based nursing teams, district general hospitals and specialist paediatric services.

Data collection and statistical analysis

Data were collected and analysed for paediatric patients ($N = 703$) who died of progressive, life-limiting conditions from the year 2000 to 2006. Data were collected for all children followed by the palliative programme, who died within the study period and for whom a location of death could be determined. The study involved evaluation of data for 318 children followed by Martin House, 233 children from Children's Hospital at Westmead and 152 children from Canuck Place, including the primary diagnosis and the location at the time of death for each patient. The statistical software package STATA was used for calculating Pearson chi-square to detect differences between location and diagnosis.

Classification of diagnosis

The child's primary diagnosis was classified into the following categories: cancer, cardiopulmonary disease, chromosomal/multi-organ syndromes, infectious/immunologic disease, metabolic/biochemical disease, neuromuscular disease and primary central nervous system

^a Data collected for Australia reflects the time period 2001–2006.

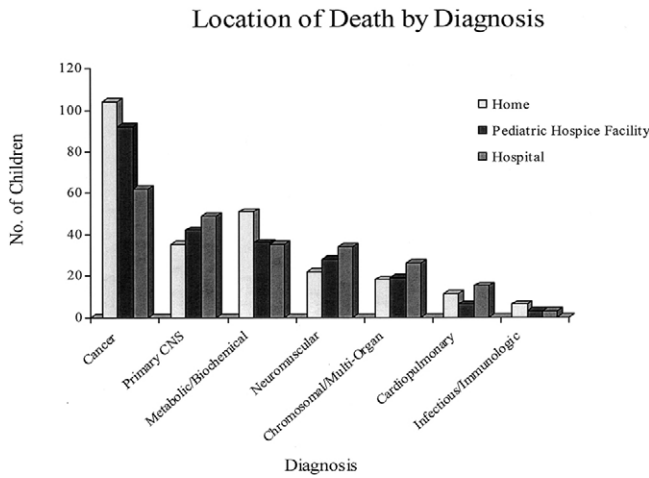


Figure 1 The location of death differed by diagnosis (Pearson chi-square = 38.1160, *P* value = 0.004).

(CNS) conditions, including static encephalopathy with severe health disturbances; these correspond to the groups described by the 2003 ACT/RCPCH Report (Association for Children’s Palliative Care/Royal College of Paediatrics and Child Health).¹²

Results

Figure 1 shows the location of death (hospital, hospice and home) and patient diagnoses for the years 2000–2006. Location of death significantly varied by underlying condition (*P* = 0.004). Paediatric cancer patients and those with metabolic or biochemical diseases were the patients most likely to die at home (40.2% and 41.1%, respectively) or in a paediatric hospice (35.5% and 29.0%, respectively). Patients most likely to die in the hospital were diagnosed with primary CNS disorders, (38.9%) neuromuscular disease (40.5%), chromosomal or multi-organ conditions (40.6%) or cardiopulmonary disorders (45.5%).

Across the three programmes there was an approximately even distribution of location of death, with 35.1% of children dying at home, 32.1% dying in a paediatric hospice and 31.9% dying in hospital, with 0.9% who died at another location. There were differences, however,

between the individual programmes as seen in Table 1. The differences between sites for the location of death by site were statistically significant (*P* = 0.000). For example, at the Children’s Hospital at Westmead palliative care programme, most children died at home (42.5%), whereas for the Canuck Place programme most died in the hospice facility (58.6%). For Martin House, home and hospital deaths were almost equal (34.6% and 35.2%).

Conclusion

This report indicates where children with a variety of progressive, life-limiting conditions actually die when given access to care in all three settings, and support for them to move freely into the setting they deem best meets their needs at a given time. Overall, an equal distribution of location of death was observed, with approximately one third of patients selecting home, hospital or hospice. Our data show that diagnosis may have an impact on chosen location for end-of-life care, with differences between cancer and non-cancer diagnoses. Families where a child has cancer appeared to prefer home first and second hospice. This preference may reflect the fact that cancer has provided the traditional model for home palliative service and perhaps also suggests an avoidance of hospital where the curative treatments took place. Children with non-cancer diagnoses, with the exception of those with metabolic diseases, were more likely to die in hospital than at any other location. Again, the factors that influence these decisions are unknown and require further study. The greater uncertainty of the trajectory for these conditions, as well as the lack of availability of home palliative care geared toward these conditions, may influence these decisions.

Even though the overall distribution was essentially even, location of death amongst the services available in each of the three programmes differed. These differences may be attributed to a number of factors, including the distance of services from home, home care availability (for example, due to nursing shortages) and local referral patterns for hospice and palliative care involvement. The differences between the three programmes may also reflect the fact that the distribution of diagnoses differed between them (data not shown). Expectations about the

Table 1 The location of death differed by site

	Home	Paediatric hospice facility	Hospital	Other
Children’s Hospital at Westmead, Australia (<i>n</i> = 233)	<i>n</i> = 99 [42.5%]	<i>n</i> = 43 [18.5%]	<i>n</i> = 91 [39.1%]	<i>n</i> = 0 [0%]
Canuck Place, Canada (<i>n</i> = 152)	<i>n</i> = 38 [25.0%]	<i>n</i> = 89 [58.6%]	<i>n</i> = 21 [13.8%]	<i>n</i> = 4 [2.6%]
Martin House, United Kingdom (<i>n</i> = 318)	<i>n</i> = 110 [34.6%]	<i>n</i> = 94 [29.6%]	<i>n</i> = 112 [35.2%]	<i>n</i> = 2 [0.6%]
Total (<i>N</i> = 703)	<i>n</i> = 247 [35.1%]	<i>n</i> = 226 [32.1%]	<i>n</i> = 224 [31.9%]	<i>n</i> = 6 [0.9%]

Pearson chi-square = 83.5264, *P* value = 0.

outcomes of different diagnoses may shape parents' plans for end-of-life care. This question as to why there were differences between the programmes and services will require further study.

One limitation of our study is that the three study settings are not equivalent in all ways. In two of the programmes (Canuck Place and Children's Hospital Westmead), the catchment areas cover large geographic areas, and community services may vary across those catchments. Therefore, access to homecare services is an area for future investigation. Another limitation is that data are extracted from charts of patients referred to the palliative care service at each programme, and does not include patients with life-limiting illness who died in the Neonatal Intensive Care Unit (NICU) or hospital, but who were never referred to the palliative care programme by their primary treatment teams. It can be the case that treating physicians do not refer a patient to palliative care programmes or that a referral is suggested but families refuse. Our data, therefore, only shows what happens once a child and family engage with these paediatric palliative care teams.

Our multi-setting study indicates that, with the provision of increasing options for place of death, the literature to date can no longer sufficiently answer the questions about where children die or what the preference for place of death is in those communities. Although it is important to know where children die, it is equally important to determine how this location aligns with the family's previously expressed preference and the impact of place of death on their quality of life. The data of our study will guide future research to examine patients' and family's preferences both for cancer and non-cancer patients in settings where the options for place of death include inpatient hospice, home or hospital.

Author contribution

Drs Siden, Collins, Miller and Straatman had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. They jointly designed and conducted the study. Dr Tucker contributed to the analysis and writing. Ms Omesi assisted with interpretation, review of the literature, prepared the manuscript and provided material support.

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analysis and interpretation of the data or in the preparation, review or approval of the manuscript.

References

- Mulhern, RK, Lauer, ME, Hoffmann, RG. Death of a child at home or in the hospital: subsequent psychological adjustment of the family. *Pediatrics* 1983; **71**: 743–747.
- Goodenough, B, Drew, D, Higgins, S, Trethewie, S. Bereavement outcomes for parents who lose a child to cancer: are place of death and sex of parent associated with differences in psychological functioning. *Psychooncology* 2004; **13**: 779–791.
- Klopfenstein, KJ, Hutchison, C, Clark, C, Young, D, Ruymann, FB. Variables influencing end-of-life care in children and adolescents with cancer. *J Pediatr Hematol Oncol* 2001; **23**: 481–486.
- Gomes, B, Higginson, IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; **332**: 515–521.
- Vickers, J, Thompson, A, Collins, GS, Childs, M, Hain, R. Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. Place and provision of palliative care for children with progressive cancer: a study by the Paediatric Oncology Nurses' Forum/United Kingdom Children's Cancer Study Group Palliative Care Working Group. *J Clin Oncol* 2007; **25**: 4472–4476.
- Higginson, IJ, Thompson, M. Children and young people who die from cancer: epidemiology and place of death in England (1995–9). *BMJ* 2003; **327**: 478–479.
- Leuthner, SR, Boldt, AM, Kirby, RS. Where infants die: examination of place of death and hospice/home health care options in the state of Wisconsin. *J Palliat Med* 2004; **7**: 269–277.
- Feudtner, C, Silveira, MJ, Christakis, DA. Where do children with complex chronic conditions die? Patterns in Washington State, 1980–1998. *Pediatrics* 2002; **109**: 656–660.
- Goldman, A, Beardsmore, S, Hunt, J. Palliative care for children with cancer—home, hospital, or hospice. *Arch Dis Child* 1990; **65**: 641–643.
- Hana, G, Bella, B, Dorit, G, Shai, I, Gideon, R, Amos, T. Integration of a palliative and terminal care center into a comprehensive pediatric oncology department. *Pediatr Blood Cancer* 2008; Published online January 31, 2008. 10.1002/pbc.21476.
- Feudtner, C, Feinstein, JA, Satchell, M, Zhao, H, Kang, TI. Shifting place of death among children with complex chronic conditions in the United States, 1989–2003. *JAMA* 2007; **297**: 2725–2732.
- Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), Royal College of Paediatrics and Child Health. *A Guide to the Development of Children's Palliative Care Services*. Bristol, UK: Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT), Royal College of Paediatrics and Child Health; 2003.