

A place to die: The case for paediatric inpatient hospices

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Thomas, a term infant born after an uneventful pregnancy, was delivered by emergency caesarian section following placental abruption. By six weeks of age, his clinical picture was suggestive of severe hypoxic-ischemic brain injury, which was supported by the finding of diffuse cerebral atrophy on computed tomography scan. Thomas' parents were informed that most likely he would never walk nor talk, never see and never safely feed by mouth. Dependent on advanced medical technology simply to remain alive, his existence would likely be short lived, and filled with frequent and prolonged hospitalizations.

After considering all options, Thomas' parents requested that no life-prolonging efforts be made; they preferred that only palliative care – treatment aimed at keeping their son comfortable – be provided. No longer requiring acute medical care, his doctors offered to arrange the support necessary to enable Thomas and his family to go home, where he could die peacefully. His parents, however, were uncomfortable with the thought of taking Thomas home and requested instead that his death occur in hospital.

For children like Thomas whose death is anticipated, considerable effort and attention has been directed at increasing the proportion who die at home, regarded by many to be the optimal location (1). This endeavour is likely due to a combination of factors: most adults prefer home as the place of death (2), parents of children who die at home report a high degree of satisfaction (3), and bereaved parents and siblings appear to adapt better when the child's death occurs at home (4,5). As a result of the focused attention directed at home care, children for whom death at home is either not possible or undesired have largely been neglected. Typically, these children must be admitted to an acute care bed where they wait, sometimes for weeks, for death to ensue. The need for a third setting, paediatric palliative care units or inpatient hospices, has received little consideration, yet this option would greatly assist in our desire to provide optimal end-of-life care.

In Canada, most dying children have two choices for end-of-life care – home or the hospital. While most adults prefer to die at home, parents of dying children may be less inclined to choose this setting due to fear of isolation or inadequate care (6). Frequent hospitalizations leading up to a child's death may lead some families to conclude (often incorrectly) that providing sufficient home care would be

impossible. Others are simply uncomfortable with the idea of having their child die at home. Even when the family is keen to have their child die at home, not all regions in Canada are able to provide the necessary home care that some children with complex medical problems require at the end of life.

When home death is not an option, generally families have no place to turn but the hospital. Unfortunately, these institutions are far from an ideal setting at the end of life. As death approaches, the goals of care should seek to maximize comfort, limit undue stress and surround the child with a loving environment. Anyone who has ever spent time in a hospital knows the atmosphere – constant beeps and bells keep patients awake, doctors and nurses are compelled to regularly examine them, and there is a limit to the number of visitors a patient can have at any given time.

Regional community hospitals often lack familiarity in providing care to dying children and as such, may be understandably reticent to do so. Perceiving this inexperience, families may also be uncomfortable turning to their local hospital at such a vulnerable time. On the other hand, tertiary paediatric hospitals would never turn away a child in need; however, in addition to being a less than ideal setting, a palliative care admission is also an inefficient use of resources. Acute care hospitals are ideal places for patients to have multiple investigations, to be assessed by various specialists and to receive treatment over short stays. The dying child, on the other hand, has very different needs and may require prolonged hospitalization (7).

Adults in Canada have long benefited from a third option when they are dying – an inpatient hospice or palliative care unit. The term 'hospice' has come to describe any dedicated end-of-life care service; it may be situated either in the home or in a specialized inpatient unit. An 'inpatient hospice' or 'palliative care unit', however, refers specifically to a place where individuals can be admitted to receive specialized physical, psychological, social and spiritual care at the end of life. It may be a separate unit within a larger hospital or an independent, free-standing structure. Designated inpatient palliative care beds are also available for some Canadian children, but only in a few select centres – Canuck Place Children's Hospice in Vancouver, British Columbia; Stollery Children's Hospital in Edmonton, Alberta; Roger's House in Ottawa, Ontario;

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Accepted for publication April 21, 2008

and the Darling Home for Kids in Milton, Ontario. Although evidence regarding paediatric hospice programs is sparse, one study concluded that dying children and their families who choose this setting for end-of-life care appreciate the “engaging activities, physical amenities and the social climate promoted by staff, volunteers and other families” (8).

Although improved funding and resources would likely increase the proportion of paediatric deaths occurring at home, inpatient hospice or palliative care services would certainly decrease the number of acute care beds currently used by dying children. A recent study (9) found that 43.9% of Canadian children referred to a palliative care service died at home – the single most common place of death. Yet, the percentage of referrals that died in an acute tertiary care setting (general and critical care units combined) was still 40%. The authors suggested that the high rate of deaths in acute care beds resulted from hospitalization remaining the ‘default option’ for most Canadian families when home palliative care was either undesired or unable to meet the needs of the child. This is cause for concern, given that a growing segment of children who will require palliative care may challenge our capacity to offer optimal end-of-life care at home.

Recent medical advances have resulted in decreased childhood deaths due to all causes. Reduced mortality, however, has been accompanied by an increase in the number of children surviving with chronic complex conditions (10,11). These children, such as Thomas, have multiple health issues, often depend on medical technology and

typically have a shortened lifespan. Today, in fact, children with complex chronic conditions account for more than 20% of paediatric deaths (1). When these children approach the end of life, they tend to require significant resources and attention. As a result of their growing numbers and the complexity of the care that they require, our ability to provide effective palliation at home for this population may become compromised.

Our ethical obligation to provide high-quality palliative and end-of-life care to children demands that an alternative setting be available when dying at home is either rejected or impossible. In most parts of Canada, this situation requires admission to an acute care bed. Although a palliative admission to an acute care centre is a compassionate and worthy undertaking when no other options exist, it may delay admission for a child in need of acute care services. In contrast, the warm environment of an inpatient hospice or paediatric palliative care unit provides an excellent alternative to end-of-life care at home. Furthermore, when not required for palliative care, these beds offer much-needed respite to families caring for children with chronic complex conditions. If we aspire to deliver the best in paediatric care, we must extend our services to meet the needs of our dying children – beginning with a place to die.

ACKNOWLEDGEMENTS: The author thanks Drs Christine Harrison and Jeremy Friedman at The Hospital for Sick Children, Toronto, Ontario, as well as the anonymous peer reviewers of *Paediatrics & Child Health* for their valuable suggestions.

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