

Location of Death in Pediatric Palliative Care: Hospital, Hospice, or Home?



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Background

When a child dies, the location of death has important implications for families' experience of death and subsequent bereavement. Location may also influence care delivery. For example, children involved with hospice are more likely to have a Do Not Resuscitate (DNR) order.¹ Factors that often influence this decision include specific condition, age at death, local area affluence, and location of home.² Often, home care for terminally ill children allows for better psychological outcomes for parents and siblings.³ Previous research suggests that parents, as well as children, prefer home as the location of death.^{4,5} However, studies of preferred or actual location of death have focused on adults, children with cancer, or settings without pediatric hospices.^{6,7}

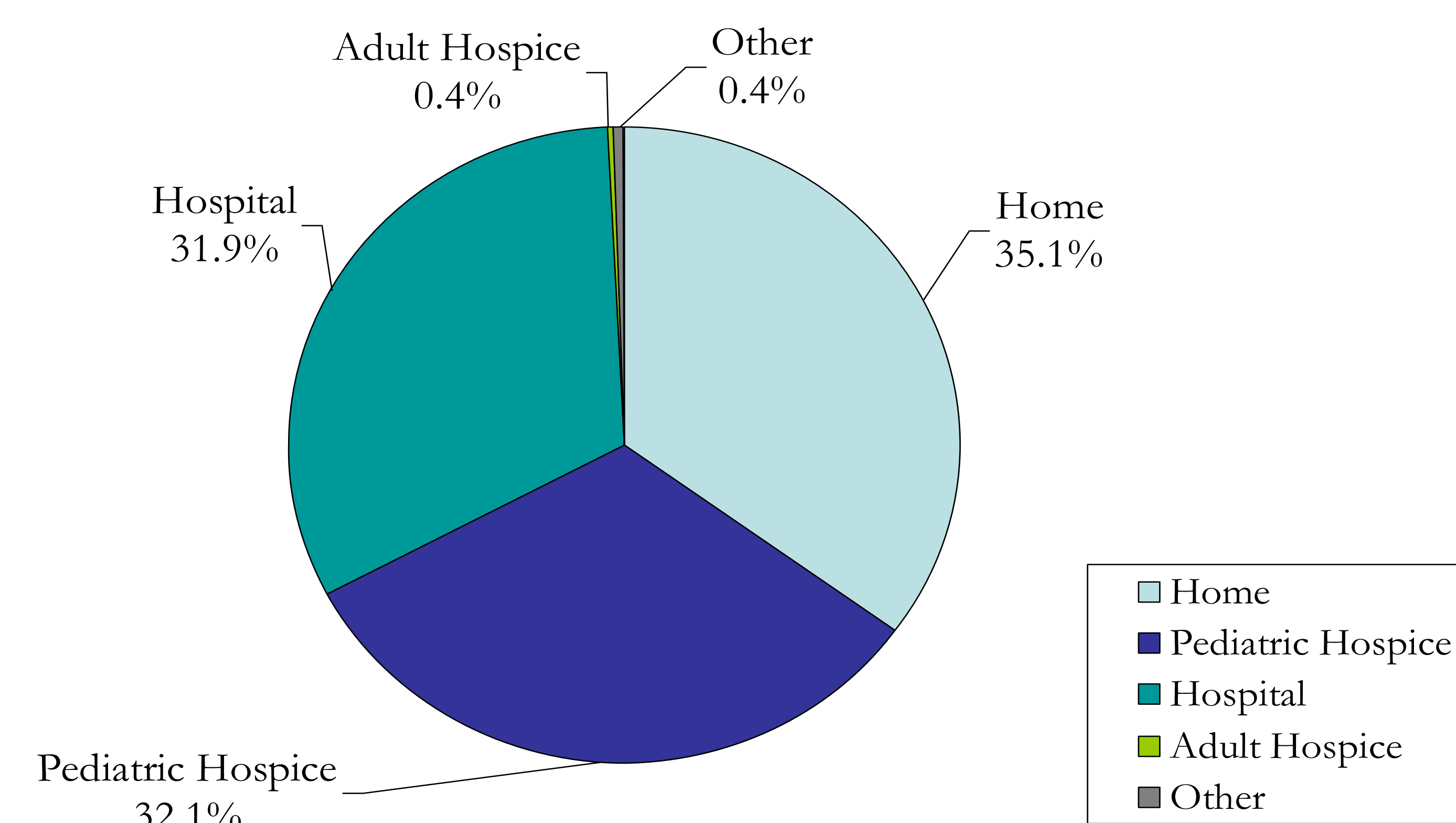
Objectives

To examine where children with a multitude of life-threatening diseases actually die when families are equally able to access hospital, pediatric hospice and care at home.

Methods

- Retrospective report on the experiences of well-established (> 10 years) pediatric hospices that are closely linked to children's hospitals and pediatric palliative care community teams.
- Hospices with these characteristics are located in several countries; here we report on programs in Australia (Children's Hospital at Westmead), Canada (Canuck Place Children's Hospice) and the United Kingdom (Martin House).
- Location of death was classified by setting, ACT/RCPC palliative group and diagnostic categories for the years 2000-2006.
- Data from a total of 703 children was collected and analyzed, with 318 children from the United Kingdom, 233 from Australia, and 152 from Canada.

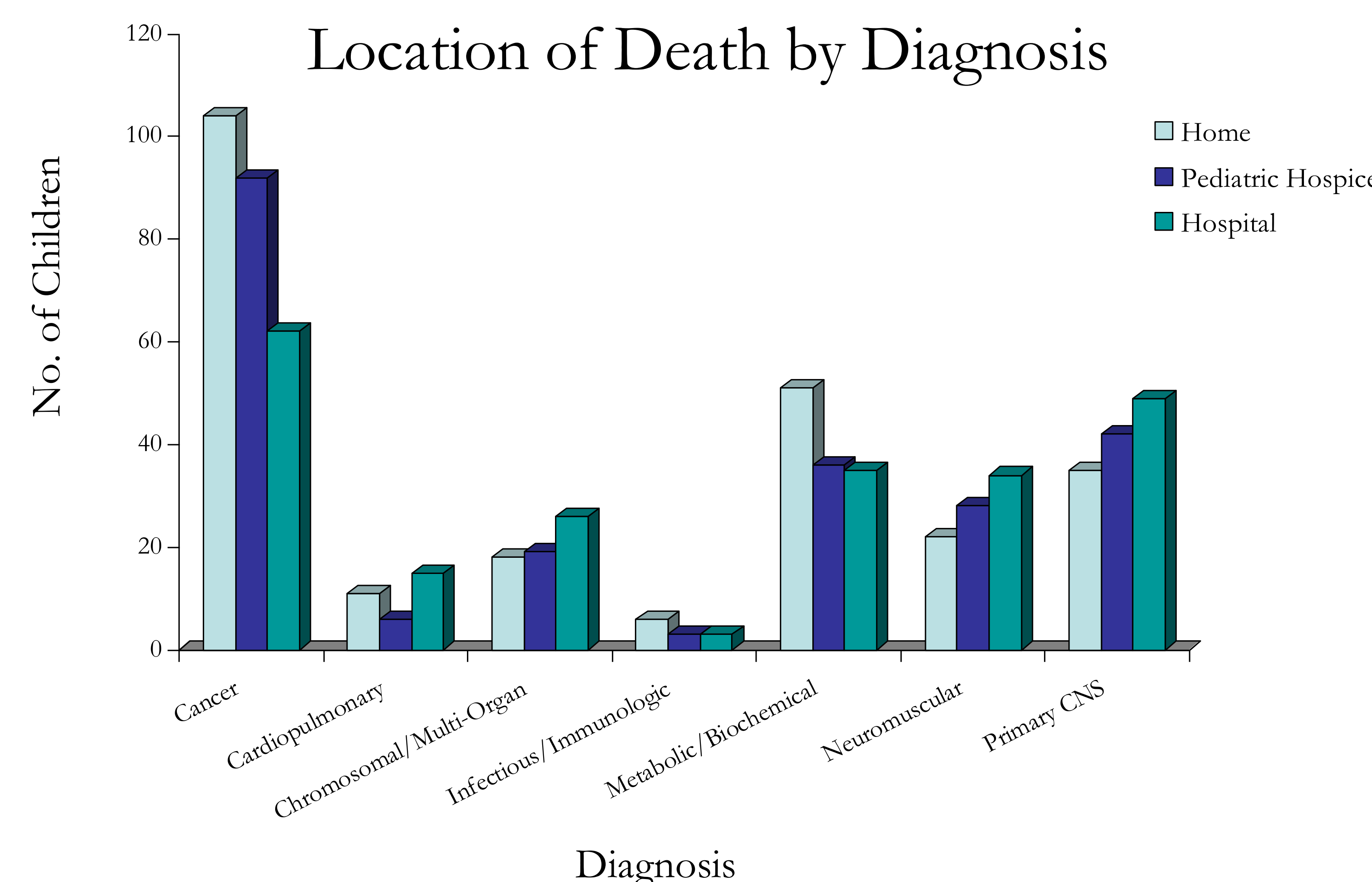
Location of Death



Findings

- Overall, 35.1% of children died at home, 32.1% died in a pediatric hospice, 31.9% of children died in hospital and 0.8% died in another location.
- Pediatric cancer patients and those with metabolic/biochemical disease were most likely to die at home or at a pediatric hospice.
- Pediatric patients diagnosed with primary central nervous system (CNS), neuromuscular, chromosomal, or cardio-pulmonary disorders were most likely to die in the hospital.

Location of Death by Diagnosis



Conclusion

- Locations of death differed between the three programs, but there was an overall even distribution of location. This suggests that families, even after entry into a palliative care program, still choose end-of-life care in different locations.
- Availability of a pediatric hospice may shift the chosen location of death away from hospital. However, the availability of a good pediatric home care program may also swing more children and families away from hospital care, as well as away from pediatric hospice care.
- These findings may be important to clinicians and care managers in determining the level and type of services available to pediatric patients in their region.
- This data may be valuable for future researchers in designing studies of where children die and the impact of location on end-of-life care and bereavement.

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