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Research

Location of death among children with life-threatening conditions: a national population-based observational study using the Canadian Vital Statistics Database (2008–2014)

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Abstract

Background: Patterns in location of death among children with life-threatening conditions (e.g., cancer, genetic disorders, neurologic conditions) may reveal important inequities in access to hospital and community support services. We aimed to identify demographic, socioeconomic and geographic factors associated with variations in location of death for children across Canada with life-threatening conditions.

Methods: We used a retrospective observational cohort design and the Canadian Vital Statistics Database to identify children aged 19 years or younger who died from a life-threatening condition between Jan. 1, 2008, and Dec. 31, 2014. We used multivariable logistic regression to determine predictors of in-hospital death for children aged 1 month to 19 years, and for neonates younger than 1 month.

Results: Overall, 13 115 decedents younger than 19 years had life-threatening conditions. Of 5250 children and 7865 neonates, 74.2% and 98.1%, respectively, died in hospital. Among children, we found a higher proportion of hospital deaths in the lowest (v. highest) income quintile (odds ratio [OR] 1.59, 95% confidence interval [CI] 1.28–1.97), and a lower proportion among children living more than 400 km (v. < 50 km) from a pediatric hospital (OR 0.73, 95% CI 0.65–0.86). Compared with Ontario, hospital death was most common in Quebec (OR 1.38, 95% CI 1.14–1.67) and least common in British Columbia (OR 0.43, 95% CI 0.34–0.53). Compared with an oncologic cause of death, all causes except neurologic and metabolic conditions had significantly higher odds of dying in hospital.

Interpretation: In addition to demographics, we identified socioeconomic and geographic differences in location of death, suggesting potential inequities in access to high-quality care at the end of life. Health care policies and practices must ensure equitable access to services for children across Canada, particularly at the end of their life.

A child's death has a long-lasting and potentially traumatic impact on families, communities and health professionals providing care.[1,2] Thus, when death in childhood is anticipated — such as when a child is living with a life-threatening condition (e.g., cancer, genetic disorders, neurologic conditions)[3] — it is important to provide high-quality care to maximize quality of life and facilitate end-of-life care and death in the preferred location.[4] In Canada, provincial studies focused on children highlight the high proportion who die in hospitals.[5–7] Variations in this proportion may reflect variation in child and family preference, but may also be influenced by availability of community services such as pediatric hospice or palliative home care, and specialized care through tertiary pediatric hospitals.[4,8,9] Although there are some conflicting findings, geography and level of income have been associated with location of death among children.[10–14] From a health equity lens, it is important to identify factors associated with location of death for children with life-threatening conditions.

We sought to identify demographic, socioeconomic and geographic factors associated with location of death in children who died from life-threatening conditions. Our goal was to identify potential health inequities and opportunities to optimize care across care settings.

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Methods

Population and cohort

This national observational, retrospective cohort study drew on the population of Canadian residents who died at 19 years of age or younger from Jan. 1, 2008, through Dec. 31, 2014. Analysts at Statistic Canada created the initial cohort using the Canadian Vital Statistics Database, a yearly census of all deaths occurring in Canada with relevant demographic information and causes of death coded using the *International Classification of Diseases, 10th Revision* (ICD-10).[15] To identify children who died from a life-threatening condition (i.e., conditions that have no cure and from which the child is expected to die or for which curative treatment may be feasible but can fail),[3] we first excluded those whose primary cause of death was listed as external, such as death by accidents, assault, suicide or drowning (ICD-10 codes from V01 to Y36), or sudden infant death syndrome (R95). Next, we combined classifications developed in the United Kingdom[16] and the United States[17] to create a list of specific ICD-10 codes within 11 categories signifying life-threatening conditions in children (Appendix 1, available at www.cmajopen.ca/content/11/2/E298/suppl/DC1). Children in the final cohort had at least 1 relevant ICD-10 code listed as a primary or contributing cause of death. Based on previous research showing that most neonates die in hospital,[4,7] we stratified the cohort to facilitate separate analysis of children (aged 29 d–19 yr) and neonates (< 29 d of age).

Outcome

We classified location of death as in a hospital (i.e., in locations licensed to operate as hospital under provincial, territorial or federal government legislation) or out of hospital (e.g., private home, freestanding birthing centre, other facility, other specified location).[18]

Predictors

We chose predictors based on previous research and available data.[6,10,13] For the child group, we categorized age as 29–364 days, 1–4 years, 5–9 years, 10–14 years and 15–19 years. For the neonates, we categorized age as younger than 24 hours and 24 hours to 28 days. We assigned decedents into 11 categories of life-threatening conditions, namely neurologic, hematologic, oncologic, metabolic, respiratory, circulatory, gastrointestinal, genitourinary, perinatal, congenital and other (e.g., systemic lupus) conditions.[16,17] For those with more than 1 relevant primary or contributing cause of death, we based assignment on the primary cause of death. In about 5% of the sample, there was no relevant primary cause and several relevant contributing causes. We developed an a priori hierarchy (Appendix 2, available at www.cmajopen.ca/content/11/2/E298/suppl/DC1) to prioritize diagnoses based on the likelihood they were a unifying cause of death (e.g., oncologic diagnoses were highest priority). We combined categories as needed to avoid small cell sizes (< 6) and preserve anonymity. Similarly, we collapsed residential provinces by region into Atlantic (Newfoundland and Labrador, Prince Edward Island, Nova Scotia and New Brunswick), Quebec, Ontario, Prairies (Manitoba and Saskatchewan), Alberta, British Columbia and the North (Northwest Territories, Yukon and Nunavut). We used the first 3 characters of postal codes to assign income quintiles according to residing neighbourhood and rurality (with a population < 10 000 classified as rural).[19] We calculated distance from a tertiary pediatric hospital using longitude and latitude data derived from the decedent's postal code and location of the nearest of 16 tertiary pediatric hospitals in Canada. We categorized distance (< 50 km, 50–199 km, 200–400 km, > 400 km) to represent increasingly complex trips (i.e., easy day trip both ways, substantial day trip both ways, trip likely involving overnight stay, overnight trip possibly involving a plane ride).[20]

Statistical analysis

We conducted all analyses using SAS (version 9.4). We summarized demographic characteristics and locations of death. We used multivariable logistic regression to model the odds of dying in hospital for each group (children and neonates). We selected model predictors a priori as described above. As we desired full model fit, we left variables in each model regardless of p value.[21] Missing data were minimal (about 2%); thus, we used complete case analysis. We undertook model diagnostics, including assessment of multicollinearity, before selecting final models for each outcome. The maximum variance inflation factor was less than 5 in all cases. All statistical tests were 2-sided; p values less than 0.05 were considered significant.

Ethics approval

The study was approved by the Health Sciences Research Ethics Board at the University of Toronto (no. 34554).

Results

Of the 23 360 children in Canada who died over the 7-year study period, 13 115 (56.1%) had a life-threatening condition (5250 children and 7865 neonates) (Figure 1). Among children aged 29 days to 19 years, 3895 (74.2%) died in hospital and 845 (16.1%) died at home. In the neonate group, 7715 (98.1%) died in hospital (Table 1). The most common causes of death in children were congenital conditions (27.7%) followed closely by oncologic conditions (25.6%). Most neonates (67.2%) died within 24 hours of birth and most (61.9%) died from a perinatal condition. Demographics are summarized in Table 1.

Predictors of dying in hospital

Results of univariate analyses are presented in Appendix 3, available at www.cmajopen.ca/content/11/2/E298/suppl/DC1. Based on multivariable logistic regression, among the child cohort (Table 2), those younger than a year of age had higher odds of in-hospital death than those aged 15–19 years (OR 1.73, 95% CI 1.40–2.15), while those aged 5–9 years had lower odds of dying in hospital (OR 0.66, 95% CI 0.54–0.82). All causes of death, other than neurologic and metabolic, had significantly higher odds of dying in hospital than cancer. The increased odds ranged from nearly double for congenital causes (OR 1.74, 95% CI 1.43–2.11) to more than 5 times

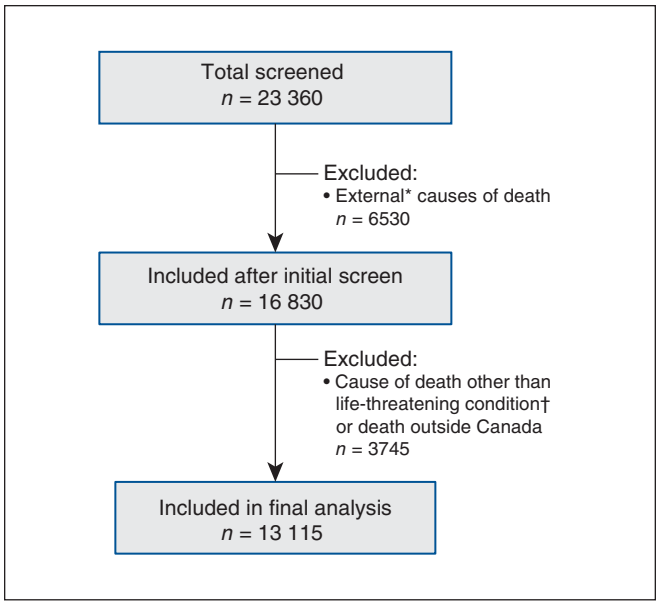

Figure 1: Flow diagram. *External causes of death included accidents, assault, suicide or drowning (*International Classification of Diseases, 10th Revision* [ICD-10] codes from V01 to Y36), or sudden infant death syndrome (R95). †Examples of causes of death other than life-threatening conditions included ill-defined or unknown causes (R99.9), depressive episodes (F32), influenza and pneumonia (J09–J18), asthma (J45–46) and infectious and parasitic diseases (A00–B99).

higher for gastrointestinal causes of death (OR 5.36, 95% CI 2.54–11.30). Compared with Ontario, those residing in BC had lower odds (OR 0.43, 95% CI 0.34–0.53), and those from Quebec had higher odds (OR 1.38, 95% CI 1.14–1.67) of dying in hospital. Children in the lowest income quintile had higher odds of dying in hospital (OR 1.59, 95% CI 1.28–1.97), compared with those in the highest quintile. Finally, those living 50–199 km (OR 0.73, 95% CI 0.62–0.86) or more than 400 km (OR 0.73, 95% CI 0.65–0.86) from the nearest tertiary pediatric hospital had lower odds of dying in hospital than those living less than 50 km away.

Among neonate decedents (Table 3), those younger than 24 hours had 13 times higher odds of dying in hospital (OR 13.0, 95% CI 7.94–21.32) than older neonates. Compared with neonates with perinatal conditions, those with congenital (OR 0.25, 95% CI 0.17–0.36) or other causes of death (OR 0.47, 95% CI 0.24–0.92) had lower odds of dying in hospital. Finally, those residing in BC had substantially lower odds of dying in hospital (OR 0.3, 95% CI 0.19–0.49) than those in Ontario.

Interpretation

Our study highlights the high proportion of children in Canada who died from a life-threatening condition in a hospital setting. Although it is not surprising that age and cause of death are significant predictors of location of death, variability based on province, income and distance from a tertiary pediatric hospital that persist after adjustment for other variables suggest potential inequities in care across the country.

Table 1 (part 1 of 2): Characteristics of study cohort

Characteristic	No. (%) of decedents*	
	Older children (aged 29 d–19 yr) *n* = 5250	Neonates (aged < 29 d) *n* = 7865
Age		
< 24 h	–	5285 (67.2)
24 h–28 d	–	2580 (32.8)
29–364 d	1700 (32.4)	–
1–4 yr	980 (18.7)	–
5–9 yr	665 (12.7)	–
10–14 yr	745 (14.2)	–
15–19 yr	1150 (22.0)	–
Sex		
Male	2440 (53.5)	4270 (54.3)
Female	2810 (46.5)	3595 (45.7)
Cause of death†		
Perinatal	305 (5.8)	4865 (61.9)
Congenital	1455 (27.7)	2690 (34.2)
Oncology	1345 (25.6)	60 (0.8)†
Hematology	120 (2.3)	
Neurology	980 (18.7)	45 (0.6)
Metabolic	345 (6.6)	65 (0.8)
Circulatory	330 (6.3)	40 (0.5)
Respiratory	195 (3.7)	100 (1.3)†
Gastrointestinal	95 (1.8)	
Genitourinary	55 (1.1)	
Other	30 (0.6)	
Province or region‡		
Ontario	2055 (39.1)	3240 (41.2)
Quebec	1095 (20.9)	2035 (25.9)
Alberta	675 (12.9)	1015 (12.9)
Prairies	520 (9.9)	600 (7.6)
British Columbia	540 (10.3)	570 (7.3)
Atlantic	320 (6.1)	350 (4.5)
North	45 (0.9)	55 (1.5)
Income quintile		
1 (lowest)	1210 (23.4)	2055 (26.7)
2	1025 (19.8)	1530 (19.9)
3	1000 (19.3)	1490 (19.3)
4	1050 (20.3)	1520 (19.7)
5 (highest)	890 (17.2)	1110 (14.1)
Rurality		
Urban	4085 (78.3)	6330 (81.7)
Rural§	1135 (21.7)	1420 (18.3)

Table 1 (part 2 of 2): Characteristics of study cohort

Characteristic	No. (%) of decedents*	
	Older children (aged 29 d–19 yr) *n* = 5250	Neonates (aged < 29 d) *n* = 7865
Distance from pediatric hospital, km		
< 50	2855 (54.8)	4700 (60.7)
50–199	1460 (28.0)	1910 (24.7)
200–400	575 (11.0)	645 (8.3)
> 400	325 (6.2)	485 (6.3)
Location of death¶		
Hospital	3895 (74.2)	7715 (98.1)
Home	845 (16.1)	60 (0.8)
Other health care facility	150 (2.9)	30 (0.4)
Other location	360 (6.9)	60 (0.8)

Note: ICD-10 = *International Classification of Diseases, 10th Revision*.
*Numbers may not add to total cohort size because of missing data. Some categories combined to avoid small cell sizes.
†Please see Appendix 1 for a complete list of included conditions for each category.
‡Prairies included Manitoba and Saskatchewan. Atlantic included Newfoundland and Labrador, Prince Edward Island, Nova Scotia and New Brunswick. North included Northwest Territories, Yukon and Nunavut.
§Population < 10 000.
¶Hospitals included facilities licensed to operate as a hospital under provincial, territorial or federal government legislation. Other health care facilities included community health centres, freestanding birthing centres, and nursing and residential care facilities. Other locations might include a school, outdoors, at a park or on route to a hospital.

In our study, the proportion of children aged 29 days to 19 years who died in hospital was 74.2%; national studies in England and New Zealand with children of similar age ranges and diagnoses found that 65.7%[22] and 53.6% of children,[10] respectively, died in hospital. This difference may be related to availability of resources like children's hospices, which are prevalent in England. Although death in hospice occurred in only 7.7% of the English cohort,[22] hospices provide supports throughout the illness, which may better enable the family to provide end-of-life care in the home. In the New Zealand study, 21% of the sample received palliative care, which was associated with a decreased risk of death in hospital.[10] The authors noted a well-established system of community supports and outreach, particularly for children with cancer.[10] Geography may also play a role; it may be easier to provide home support to children over a smaller geographical area.

In our study, almost all neonates (98%) died in hospital — many within the first 24 hours of life from a perinatal condition such as birth trauma, infection or asphyxia — leaving little opportunity to facilitate end-of-life care outside the hospital. Neonates with congenital conditions were more likely to die at home, suggesting that antenatal diagnosis and clearer prognosis may facilitate advanced care planning and out-of-hospital care. Studies have described a link between home death and improved bereavement outcomes, such as reduced depression, anxiety and complicated

Table 2: Multivariable logistic regression of factors associated with death in hospital among children (aged 29 d–19 yr), *n* = 5250*

Characteristic	OR (95% CI)
Age	
15–19 yr	Ref.
10–14 yr	0.95 (0.77–1.17)
5–9 yr	0.66 (0.54–0.82)
1–4 yr	0.88 (0.72–1.07)
29–364 d	1.73 (1.40–2.15)
Sex	
Male	Ref.
Female	1.06 (0.93–1.21)
Cause of death	
Oncology	Ref.
Congenital	1.74 (1.43–2.11)
Neurology	1.07 (0.90–1.28)
Metabolic	1.12 (0.86–1.46)
Circulatory	2.73 (1.96–3.79)
Perinatal	2.78 (1.84–4.21)
Respiratory	3.37 (2.15–5.31)
Hematology	2.52 (1.49–4.26)
Gastrointestinal	5.36 (2.54–11.30)
Genitourinary	3.44 (1.43–8.26)
Other	3.34 (1.15–9.68)
Region of residence	
Ontario	Ref.
Quebec	1.38 (1.14–1.67)
Alberta	1.03 (0.83–1.27)
Prairies	1.27 (0.98–1.63)
British Columbia	0.43 (0.34–0.53)
Atlantic	1.02 (0.76–1.37)
North	0.49 (0.23–1.05)
Income quintile	
5 (highest)	Ref.
4	1.08 (0.88–1.33)
3	1.07 (0.87–1.32)
2	1.23 (0.99–1.52)
1 (lowest)	1.59 (1.28–1.97)
Rurality	
Urban	Ref.
Rural	0.98 (0.81–1.18)
Distance from pediatric hospital, km	
< 50	Ref.
50–199	0.73 (0.62–0.86)
200–400	0.87 (0.68–1.11)
> 400	0.73 (0.65–0.86)

Note: CI = confidence interval, OR = odds ratio, Ref. = reference.
*< 2% missing data, degrees of freedom = 29, C-statistic = 0.69.

Table 3: Multivariable logistic regression examining factors associated with death in hospital among neonates (aged < 29 d), *n* = 7865*

Characteristic	OR (95% CI)
Age	
< 24 hr	13.01 (7.94–21.32)
24 hr–28 d	Ref.
Sex	
Male	Ref.
Female	0.75 (0.53–1.05)
Cause of death	
Perinatal	Ref.
Congenital	0.25 (0.17–0.36)
All other causes	0.47 (0.24–0.92)
Region of residence	
Ontario	Ref.
Quebec	1.36 (0.79–2.34)
Alberta	0.53 (0.31–0.88)
Prairies	0.97 (0.49–1.92)
British Columbia	0.30 (0.19–0.49)
Atlantic	1.54 (0.53–4.45)
North	0.27 (0.05–1.42)
Income quintile	
5 (highest)	Ref.
4	1.24 (0.70–2.18)
3	1.33 (0.75–2.35)
2	1.57 (0.88–2.83)
1 (lowest)	1.16 (0.69–1.94)
Rurality	
Urban	Ref.
Rural	0.73 (0.45–1.19)
Distance from pediatric hospital, km	
< 50	Ref.
50–199	0.66 (0.43–1.01)
200–400	1.08 (0.56–2.12)
> 400	0.89 (0.41–1.94)

Note: CI: confidence interval, OR = odds ratio, Ref. = reference.
*< 2% missing data, degrees of freedom = 18, C-statistic = 0.87.

grief,[4] highlighting the importance of improving access to end-of-life care at home even for families of neonates. Increased community support, including availability of free-standing hospices, may offer families additional options for location of care and death.[23]

As described in other research,[10,11,22] children with cancer were more likely to die outside the hospital, possibly because of the more predictable illness trajectory, with more opportunities to plan and provide supports to facilitate a home death. Other diagnoses (e.g., congenital illnesses) may have a more unpredictable disease course. Challenges in identifying the terminal phase of an illness may be associated with less opportunity or desire for a home death.[4,11]

Although Canada has publicly funded health care systems that are meant to be accessible to all people in Canada regardless of where they live, we noted differences in location of death based on province and distance from a tertiary pediatric hospital. The decreased odds of a hospital death in BC may reflect the presence of Canuck Place Children's Hospice, North America's first freestanding children's hospice, which opened in 1995 and provides residential palliative care and respite, as well as consultation and outreach across the province.[24] Other research has noted a trend toward an increased number of home deaths for children when a well-developed system of pediatric palliative care services was available, both in hospitals and within community settings.[10,25–27] Palliative care, other specialty services and family supports such as Ronald McDonald Houses are concentrated in the 16 tertiary pediatric hospitals across Canada. As in other studies, we found that those living further from these tertiary hospitals were less likely to die in hospital.[6,12] Living very close (e.g., < 50 km) may facilitate relatively easy returns to the hospital, where care is provided by health care professionals who are well known to the family, possibly resulting in reluctance to develop new relationships with community-based providers. Given the challenges of travelling long distances when a child is nearing death, it is possible that those living furthest (e.g., > 400 km) from a tertiary hospital may be more likely to remain home if community supports are in place. Further research is needed to examine distance from hospital as a factor in decision-making about location of death.

Findings in previous research about the impact of socioeconomic status on location of death are conflicting.[10,13] However, consistent with our study, a recent meta-analysis found that those living in neighbourhoods with the lowest income quintiles were more likely to die in hospital.[11] Across studies, it is unclear what mechanisms may underlie this disparity; however, patient and family preference, system issues, provider biases or some combination of these factors may be at play.[14] In one Canadian study of 75 children with cancer, lower income was associated with parent preference for death in hospital.[28] Bona and Wolfe[29] suggested that underserved populations may have differential access to palliative care supports, both in the community and in the hospital, and when support is provided there may be differences in the degree of benefit they experience from advanced care planning and efforts to improve quality of life. More research is needed to examine factors underlying socioeconomic status and their contribution to care inequities.

Limitations

Our data do not reflect the growth and development of pediatric palliative care in the last 8 years and its potential impact on supports available to children and families in their chosen location of care.[30] However, this study provides an important baseline examination of location of death that can be used to study changes in the future.

Only death record data for decedents were available nationally. Our analysis was limited to variables available in this data set and did not include potentially relevant factors such as race, ethnicity or religion. Potential inequities based on income and geography should be explored in provincial samples to provide a more fulsome description of other factors influencing end-of-life care and location of death. Death records are also limited in the specificity of location of death outside of a hospital. For example, hospices provide an important alternative to both hospital and home but cannot be examined separately with current data.[9] Administrative data do not allow for evaluation of the preferences of children or parents about location of death or the suitability of a non-hospital death. Unknown details of illness or preference could potentially confound the association between hospital death and income or location. Finally, a very small number of neonates died outside of a hospital, thus limiting the power and stability of the logistic regression model for this cohort.

Conclusion

Location of death is a common marker of quality of end-of-life care.[31–33] Not all children or their parents prefer to be at home;[4,8] however, given the link to potentially improved bereavement outcomes both for parents and siblings,[4] it is important that families of children with life-threatening conditions are given the opportunity to be home if they so choose. Although the *Canada Health Act*[34] includes the principles of universality, comprehensiveness and accessibility, our study highlighted concerning differences in the likelihood of children's deaths occurring in hospital across measures of income, province of residence and distance from tertiary pediatric hospital. These differences may signify a lack of systematic access to both hospital and community-based services, including specialized pediatric palliative care teams, pediatric hospices and palliative home care. The geographically dispersed population of Canada requires greater efforts to ensure health care principles are applied to all people in Canada and, particularly, vulnerable children and their families.

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