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

Article Authors: Kimberley Widger PhD, Sarah Brennenstuhl PhD, Peter Tanuseputro MD, Katherine E. Nelson MD PhD, Adam Rapoport MD, Hsien Seow PhD, Harold Siden MD MHSc, Chris Vadeboncoeur MD, Sumit Gupta MD PhD

Reviewer 1: Roger Thomas/University of Calgary, Family Medicine

Comments

Thank you for this important study. As with any database study the questions are about which variables were available to be assessed and the degree of certainty with which the interpretations which can be made.

Thank you.

Introduction

“– 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 heavily influenced by availability of community services such as pediatric hospice or palliative home care, as well as specialized care through tertiary pediatric hospitals. Based on research conducted in the United States and other countries, geography and level of income may also impact on where children die.¹⁰⁻¹⁴ From a health equity lens, it is important to identify factors associated with location of death for children with life-threatening condition in Canada.”

Your literature review is brief. The word “may” occurs three times in this paragraph. Please discuss the certainty of evidence about your statement

Our use of ‘may’ in the first two instances reflects the current state of knowledge about the impact of child and family preference vs availability of services. Two of the citation were for systematic reviews both of which concluded that more research is needed to understand family preference and other factors associated with location of death. We changed the sentence referencing the role of geography and level of income to remove “may” and indicate that there are conflicting findings on the impacts of these variables on location of death.

Data

Please explain why your sample is from 1 Jan 2008 to 31 Dec 2014. Why not up to date?

Our sample reflects data available at the time the study was funded which was in 2016. There have been several delays in finalizing the analysis for publication (e.g., lag time from data collection to availability for analysis, then an additional year to get access to the data, 18-month parental leave, bereavement leave, COVID shutdown of the data centre).

Accessing more recent data particularly at the provincial level, which includes a wider variety of variables, is the focus of future work. However, we believe it is critically important to publish baseline information up to 2014 to provide context and comparison data for future work.

Please explain why you excluded accidents, assault, suicide and drowning as some may reflect inadequate parental care/abuse (you also excluded SIDS).

We focused on life-threatening conditions where death could have been somewhat anticipated and presumably there was time for discussion about preferences for location of death. In the case of accidents, assault, suicide, and drowning, one would expect death to appropriately occur in hospital following life-saving efforts. In the case of SIDS, death likely occurred at home – but not due to a planned process. In both cases, death was not anticipated and therefore less relevant to our research question.

Please explain why you did not assess the effect of ethnicity as this may affect the desire/acceptance for home/vs hospital care. Can you assess First Nations and Métis children's outcomes?

While ethnicity may play a role in decision-making about location of care, data on ethnicity and First Nations/ Métis status were not available. We have added lack of data on ethnicity (as well as race and religion) as a limitation of the study.

Results

The probability of death outside a hospital was statistically different for only two provinces (BC $<.001$ and Quebec $.001$); for two of three distances from a pediatric hospital (50-199 km. $<.001$, and > 400 km $<.001$), and for only the two lowest income quintiles 2 ($.054$) and 1 ($.001$) and surprisingly not for urban/rural ($.806$).

Which variables could explain these differences?

There is not sufficient space to provide and in-depth exploration and discussion on the possible mechanisms of each of our findings in the interpretations section. However, we have added some details in relation to provincial differences and the concentration of services at tertiary centres (including Ronald McDonald House). In terms of the lack of difference due to rurality, given the small number of pediatric hospitals across the country, there are rural areas within 2 hours of a hospital (e.g., particularly in Saskatchewan and Manitoba) but there are also cities that are more than 4 hours away (e.g., Thunder Bay is 15 hours from Ottawa and 7 hours from Winnipeg). We have drawn on underlying mechanisms proposed by authors of others with similar findings about the impact of income levels. We are not able to test these mechanisms with the dataset available for this study but have noted the need for further research in each of these areas to identify variables that may underly these differences.

Do you have evidence on the % characteristics of families (especially by the characteristics you assessed) who state a preference or strong preference for a home death to support your conclusion?

We found one study in families of children with cancer that explored characteristics of the family in relation to their preference (others simply looked at preference, congruence between child and parent preference, and congruence between preferred and actual location of death). In the one relevant study those with a lower income preferred death in hospital; we have added this information to the interpretation.

9. A study of children in foster care in Alberta and BC showed a higher-than-expected rate of death. Do you have any data on these children?

Unfortunately, data on whether children were in foster care was not part of the dataset.

One typo page 5 data was (Latin datum = singular, data = plural)

The sentence was corrected.

Reviewer 2: Conall Francouer /CHUL, Pediatrics

Comments

In this Canadian retrospective observational study, the authors aimed to identify demographic, socioeconomic and geographic factors that are associated with variations in locations of death for children with life-threatening conditions. Using database data, the authors were able to highlight geographic and socioeconomic disparities that may suggest unequal access to high quality care at end-of- life. These findings are important and merit publication.

Feedback

- The authors clearly describe the basis for this study.
- The authors clearly describe their methodology and dichotomize their results by neonate and non-neonate populations, which is appropriate and makes the findings more easily interpretable.
- Despite being database-based, the authors report an impressive missing data rate of only 2%.

Overall, the authors clearly present their findings and nicely present them within the Canadian context

Thank you

Comments or revisions

1. The major flaw in this study is that the data is relatively old (2008-2014) but the authors address this clearly at the beginning of the limitations section. Though outdated, I do believe these findings are important and as the authors state, will be useful as a baseline for future comparison

Thank you

2. In the results (page 7, under predictors of dying in hospital), some of the wording could be clarified so that the section reads more clearly (e.g. compared to an oncologic cause of death...)

We have clarified the wording throughout this section.

3. In the Interpretation section (page 8), the authors could speculate why their findings differ from those in England and New Zealand

We have added some possible reasons for the differences in the Interpretation section.