

Infants, children, youth and young adults with a serious illness in British Columbia: a population-based analysis using linked administrative data

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Abstract

Background: Pediatric palliative care aims to improve quality of life among infants, children, youth and young adults with serious illnesses, sometimes over years, but estimates of infants, children, youth and young adults requiring pediatric palliative care have been highly variable and need refinement. We sought to describe this population in British Columbia and identify clinical instability to inform program planning in pediatric palliative care.

Methods: We conducted a population-based analysis using linked administrative health data from 2012/13 to 2016/17. We applied a coding framework validated in the United Kingdom to estimate the number of BC residents aged 0–25 years with serious illnesses and to identify 5 clinical stages. We describe demographics, estimate prevalence and model risk of instability, defined as having urgent hospital admissions, admissions to the intensive care unit or death.

Results: About 2500 infants, children, youth and young adults were admitted to hospital with a serious illness diagnosis each study year, of which around 50% were infants, 60% or so of whom had perinatal or congenital diagnoses. Compared with children aged 1–4 years, infants had the highest risk of instability (odds ratio [OR] 6.59, 95% confidence interval [CI] 5.97–7.29). Compared with oncology patients, infants, children, youth and young adults with neurological (OR 1.43, 95% CI 1.21–1.70) and otherwise specified diagnoses (OR 1.55, 95% CI 1.39–1.73) had a higher risk of instability.

Interpretation: The population of infants, children, youth and young adults with serious illnesses in BC is substantially larger than that currently receiving pediatric palliative care. Future planning of these services needs to consider expanding its reach, focusing particularly on infants and other subpopulations with high risk of instability.

Pediatric palliative care works to improve quality of life among infants, children, youth and young adults with serious illnesses through the prevention and relief of suffering. Pediatric palliative care identifies and treats physical and psychosocial symptoms and supports families, including provision of bereavement support.¹ Pediatric palliative care encompasses more than the final days of life, providing comprehensive care for infants, children, youth and young adults and their families for as long as necessary, in many cases over years.^{2–8} Identifying all who would benefit from pediatric palliative care input earlier in their journey is beneficial to both patients and their families, and is needed to inform health and social services planning.^{9,10}

There is an ongoing discussion about the ideal term to describe the health conditions relevant to pediatric palliative care, including life-limiting conditions,¹¹ life-threatening conditions¹² and serious illnesses. We will use the term serious illnesses for health conditions, acquired before birth or during childhood, that put infants, children, youth and young adults at risk of dying before adulthood, and should therefore be assessed for pediatric palliative care services.

Although attempts have been made to estimate the size of the service population,¹³ the number of infants, children, youth and young adults with serious illnesses in Canada is unknown. Previous international research has provided estimates of the prevalence of children eligible for pediatric palliative care ranging from 3.75 to 95.7 per 10000 people.^{14,15} We sought to use a framework developed and applied in the United Kingdom,^{14,16} with the objective of providing an estimate of the number of infants, children, youth and young adults living with serious illnesses in British Columbia. We also sought to describe the population demographics, health care use and risk of instability, defined as having urgent hospital admissions, stays in the intensive care unit (ICU) or death.

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Methods

Study design

We used population-based, individual-level, linked administrative health data to describe the population of infants, children, youth and young adults (aged 0–25 yr) living with serious illnesses in BC from fiscal year 2012/13 to 2016/17 and to explore factors associated with risk of instability. Our study period was Apr. 1, 2012, to Mar. 31, 2017. We considered 5 years to be a reasonable time frame to observe changes over a stable period of health service delivery before the COVID-19 pandemic.

Setting

In 2017, the province of BC had an estimated population of 4.9 million, of which 1.4 million (28%) people were between the ages of 0 and 25.¹⁷ The Medical Services Plan (MSP) is BC's provincial health insurance program, which covers health care benefits for eligible BC residents who meet conditions.¹⁸

Patients requiring pediatric palliative care in BC have access to Canuck Place Children's Hospice, a province-wide nonprofit program that provides respite, specialist symptom management, end-of-life care and bereavement in 2 hospice locations, in families' homes,¹⁹ through BC Children's and BC Women's Hospitals' inpatient and outpatient services²⁰ and through regional hospitals.²¹

Data sources

Population Data BC provided linked, deidentified, administrative data for this study. We obtained data from the Discharge Abstracts Database (DAD),^{22,23} the National Ambulatory Care Reporting System (NACRS) data set,²⁴ the MSP payment file,²⁵ the Vital Statistics Deaths data set,²⁶ the PharmaNet data set²⁷ and Population Data BC's Consolidation File.²⁸ Appendix 1 (available at www.cmajopen.ca/content/11/6/E1118/suppl/DC1) provides more information.

Population Data BC uses a combination of deterministic and probabilistic linkage to collect records across data sets.^{29,30} They supply a unique identifier to the research team, which permitted us to connect individuals across data sets.

Study population

We used a coding framework developed by Fraser and colleagues^{14,16} to identify people with serious illnesses of interest in a pediatric population. The framework is based on codes from the *International Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)* applied to infants, children, youth and young adults using hospice-palliative care in the UK.¹⁶

We defined the study population as infants, children, youth and young adults aged 0–25 years, living in BC, with any diagnostic code for a serious illness (within the coding framework, Appendix 2, available at www.cmajopen.ca/content/11/6/E1118/suppl/DC1) recorded during a hospital admission within the study period. We consider infants, children, youth and young adults registered for public health insurance, with

prescriptions (PharmaNet records) or those receiving services provided by fee-for-service practitioners (MSP payment file records) to be living in BC.

For reporting the size and characteristics of this population over time, we analyzed patients who received a diagnosis of a serious illness during an inpatient hospital visit in a given year. For calculating prevalence and modelling the risk of instability, we considered all infants, children, youth and young adults who received a diagnosis of a serious illness during an inpatient hospital visit in a 5-year time frame, between Apr. 1, 2012, and Mar. 31, 2017.

Variables

Demographics

We obtained patients' date of birth, sex and socioeconomic status (based on neighbourhood income quintiles) from Population Data BC's Consolidation File. It was not possible to distinguish between assigned sex, legal sex and gender based on this information. We calculated age as of Mar. 31 or the date of death, when applicable. We grouped age according to generally accepted age groups for pediatric populations.^{31,32}

Serious illnesses

The coding framework clusters diagnoses assigned during hospital admissions (in the DAD) into 11 groups. Every year, we assigned patients to a primary (i.e., most frequent) diagnostic group. We assigned patients to "multiple" when they had more than 1 modal diagnostic group during a given year. In addition, we found that many pediatric diagnoses of relevance were assigned to the ICD-10 congenital group rather than to an organ system. For example, most pediatric heart defects were assigned to congenital (Q00–99) rather than circulatory (I00–99). Therefore, we combined several coding groups that obscured the underlying condition or had small numbers. Thus, we merged 7 coding groups (hematology, genitourinary, respiratory, gastrointestinal, circulatory, other, and multiple) into a new taxonomic unit labelled otherwise specified (Appendix 2). For the model, if a person did not have a primary diagnostic category in a given year, we assigned the taxonomic unit from the closest preceding year, if applicable, or the closest subsequent year otherwise (Appendix 3, available at www.cmajopen.ca/content/11/6/E1118/suppl/DC1).

Clinical stages

In 2017, Jarvis and colleagues,¹⁴ using UK data, defined 4 clinical stages (stable, unstable, deteriorating and dying) based on health care utilization. We adapted this approach, distinguishing between emergency department visits and urgent or unplanned admissions, thereby identifying the following 5 clinical stages for this study: stable, meaning that the patient was not in any of the other stages at any point during a given year; unstable (emergency department), meaning that the patient had emergency department visits during a given year, not leading to hospital admission; unstable (hospital admission), meaning that the patient had urgent or unplanned inpatient admissions during a given year,

not including ICU admissions; deteriorating, meaning that the patient had unplanned ICU admissions during a given year; and died, meaning that a death date was recorded.

We obtained data on hospital and ICU admissions from the DAD, and data on emergency department visits from the NACRS table as the primary source, and from the MSP payment file and the DAD as supplementary sources. We obtained dates of death from the Vital Statistics Deaths data set, and from the DAD and the NACRS data sets as supplementary sources. For each patient, we recorded the most severe clinical stage for every year.

Statistical analysis

We generated a frequency table characterizing the population of infants, children, youth and young adults with serious illnesses, reporting the number and percentage for each demographic variable by study year.

We calculated the 1-year period prevalence of infants, children, youth and young adults with serious illnesses per 10 000 people for the 2016/17 fiscal year. In addition, we calculated the yearly rate of hospital admissions. We determined the population at risk from census-derived mid-year estimates.^{17,33}

We created a binary outcome variable by collapsing patients in the stable and unstable (emergency department) stages in 1 group, and those in the unstable (hospital admission), deteriorating and died stages in another. We considered patients in the unstable (emergency departments) stage similar enough to those in the stable stage to be grouped together because, in BC, people go to the emergency department for many reasons aside from the severity of the illness (e.g., out-of-office hours, long waiting times to see a clinician). We used generalized estimating equations, specifying first-order autoregressive correlation to model risk of instability, and accounting for correlation of observations within individuals and possible dependence across years. We included sex, age group, socioeconomic status and taxonomic unit as predictors. We report unadjusted odds ratios from single predictor models and adjusted odds ratios from the multivariable model.

We chose the second youngest age group (1–4 yr) as the reference category to compare both infants (aged < 1 yr) and older groups. We chose oncology as the reference category for taxonomic unit because the epidemiology is well known.^{34,35}

For each year, we excluded patients from the models if they had missing data for any variable.

Initially, we captured a large group of neonates using the described methodology, more than we report here. Additional exploration found that many were assigned ICD-10 code P28.5 (respiratory failure of newborn); however, in most cases where this was the only code assigned, or when it was combined with 6 other specific ICD-10 codes (Appendix 4, available at www.cmajopen.ca/content/11/6/E1118/suppl/DC1), there were no further emergency department visits or urgent hospital admissions, suggesting that their health improved. We removed these patients from the study as they would not need pediatric palliative care.

We accessed and analyzed the data through Population Data BC's Secure Research Environment, using SAS Statistical Software version 9.4 (SAS Institute) using the GENMOD procedure.

Ethics approval

This study was approved by the University of British Columbia Research Ethics Board (no. H18–00645).

Results

The number of infants, children, youth and young adults with a serious illness diagnosis during an inpatient hospital visit remained stable over time at around 2500 patients each year. Neonates and infants accounted for more than half of this population. The number of patients with newly diagnosed serious illness greatly decreased after 1 year of age, and continued to decline gradually until adolescence, when it increased. A lower percentage of patients in the study lived in neighbourhoods of the highest income group (13.9%–17.6%) each year, than in the general population (20%). Around 60% of the patients had perinatal or congenital diagnoses each year (Table 1).

Clinical stages

On average, patients in the unstable (hospital admission), deteriorating and died stages constituted 28% of the study population, and are those in greater need for palliative care (Table 2).

Prevalence and rate of hospital admissions

In 2016/17, 9940 infants, children, youth and young adults were living with a serious illness in BC, based on a hospital diagnosis made between Apr. 1, 2012, and Mar. 31, 2017. This results in a prevalence of 73.1 per 10 000 population. Reflecting the different acuity levels and service needs, 2457 of these patients had at least 1 hospital visit during that year. Thus, while around 25% of this population requires hospital admissions each year, the rest of the group, in the community, might still benefit from pediatric palliative care.

The rate of hospital admissions was higher among infants than children and young adults (Table 3). We recalculated this rate without the infant group, many of whom may be cared for entirely within the neonatal intensive care environment. Excluding infants, the rate of hospital admissions for patients aged 1–25 years was 9.1 per 10 000 population, on average.

Modelling

Compared with people aged 1–4 years, infants had the highest risk of instability and patients aged 15–25 years had an increased risk of instability. We found a similar risk of instability as infants among those aged 5–14 years (Table 4).

Compared with patients with oncologic diagnoses, patients with perinatal and congenital diagnoses had lower risk; those with neurological and the otherwise specified diagnoses had a higher risk of instability, and those with metabolic diagnoses showed a similar risk.

Sex and socioeconomic status were not significant predictors of instability.

Table 1: Demographic characteristics of infants, children, youth and young adults who had a serious illnesses code recorded during a hospital admission in British Columbia by fiscal year

Characteristic*	No. (%) of patients				
	2012/13 n = 2455	2013/14 n = 2508	2014/15 n = 2509	2015/16 n = 2448	2016/17 n = 2457
Age group, yr					
< 1	1252 (51.0)	1334 (53.2)	1375 (54.8)	1276 (52.1)	1242 (50.5)
1–4	340 (13.8)	315 (12.6)	278 (11.1)	285 (11.6)	294 (12.0)
5–9	147 (6.0)	155 (6.2)	171 (6.8)	164 (6.7)	176 (7.2)
10–14	150 (6.1)	142 (5.7)	135 (5.4)	138 (5.6)	131 (5.3)
15–19	217 (8.8)	210 (8.4)	200 (8.0)	221 (9.0)	245 (10.0)
20–25	349 (14.2)	352 (14.0)	350 (13.9)	364 (14.9)	369 (15.0)
Sex					
Male	1378 (56.1)	1423 (56.7)	1368 (54.5)	1364 (55.7)	1368 (55.7)
Female	1077 (43.9)	1085 (43.3)	1141 (45.5)	1084 (44.3)	1089 (44.3)
Socioeconomic status†					
1 (lowest income group)	554 (22.6)	536 (21.4)	527 (21.0)	565 (23.1)	512 (20.8)
2	517 (21.1)	514 (20.5)	562 (22.4)	518 (21.2)	479 (19.5)
3	474 (19.3)	478 (19.1)	487 (19.4)	459 (18.8)	492 (20.0)
4	492 (20.0)	526 (21.0)	496 (19.8)	524 (21.4)	499 (20.3)
5 (highest income group)	389 (15.8)	430 (17.1)	404 (16.1)	341 (13.9)	432 (17.6)
Missing or unknown	29 (1.2)	24 (1.0)	33 (1.3)	41 (1.7)	43 (1.8)
Taxonomic unit					
Perinatal	1003 (40.9)	1052 (41.9)	1121 (44.7)	1032 (42.2)	980 (39.9)
Congenital	444 (18.1)	458 (18.3)	436 (17.4)	434 (17.7)	456 (18.6)
Oncology	390 (15.9)	401 (16.0)	380 (15.1)	393 (16.1)	413 (16.8)
Neurology	134 (5.5)	128 (5.1)	112 (4.5)	122 (5.0)	125 (5.1)
Metabolic	32 (1.3)	26 (1.0)	31 (1.2)	29 (1.2)	30 (1.2)
Otherwise specified	452 (18.4)	443 (17.7)	429 (17.1)	438 (17.9)	453 (18.4)

*We did not find missing data for age, sex or taxonomic unit. Less than 1.8% of patients had missing data for socioeconomic status in any year.
†Based on neighbourhood income quintile.

Interpretation

This study presents the number of infants, children, youth and young adults in BC living with serious illness, as described by a coding system developed and validated in the UK. Each year of the study, roughly 2500 patients aged 0–25 years who were living with serious illness in BC had inpatient hospital visits. Those in the 3 most severe clinical stages accounted for 28% of this population on average, and the yearly prevalence of infants, children, youth and young adults with serious illnesses was around 73 per 10000 people. Between fiscal years 2016/17 and 2019/20, 579 infants, children, youth and young adults received services through Canuck Place at some point,³⁶ indicating that while many of these at-risk patients are being cared for, there are others still in need. These results will be useful in guiding the future provision of pediatric palliative care in BC and are

likely to apply to other Canadian provinces that share similar population and health system characteristics.

The coding system we used is distinct, based on its focus on pediatric palliative care rather than the broader group of children with medical complexity, and by the fact that the clinician-derived ICD codes were validated against a population from a pediatric palliative care program.¹⁶ Our work parallels that of Fraser and colleagues,¹⁴ demonstrating the utility of the approach.

Our work aligns with recent findings outside of North America. Researchers in Korea identified similar results to ours, with a prevalence of 95.5 per 10000 children with life-limiting conditions.³⁷ Their data included patients in the stable, non-hospitalized group, so the prevalence would be expected to be larger. They also found that infants make up the largest group. In an examination of pediatric ICU data in the UK, children with serious illnesses comprised most admissions (58%) and

Table 2: Infants, children, youth and young adults who had a serious illnesses code recorded during a hospital admission in British Columbia by clinical stage and fiscal year

Clinical stage	No. (%) of patients				
	2012/13 <i>n</i> = 2455	2013/14 <i>n</i> = 2508	2014/15 <i>n</i> = 2509	2015/16 <i>n</i> = 2448	2016/17 <i>n</i> = 2457
Stable	809 (33.0)	866 (34.5)	880 (35.1)	761 (31.1)	741 (30.2)
Unstable (emergency department)	956 (38.9)	960 (38.3)	948 (37.8)	994 (40.6)	1037 (42.2)
Unstable (hospital admission)	192 (7.8)	197 (7.9)	176 (7.0)	148 (6.0)	138 (5.6)
Deteriorating	417 (17.0)	380 (15.2)	425 (16.9)	449 (18.3)	432 (17.6)
Died	81 (3.3)	105 (4.2)	80 (3.2)	96 (3.9)	109 (4.4)

Table 3: Rate of hospital admissions of infants, children, youth and young adults who had a serious illnesses code recorded during a hospital admission in British Columbia by age and fiscal year

Group	Rate of hospital admissions per 10000 population				
	2012/13	2013/14	2014/15	2015/16	2016/17
Age group, yr					
< 1	286.7	302.0	312.6	284.7	276.4
1–4	18.9	17.6	15.4	15.7	15.9
5–9	6.6	6.9	7.5	7.0	7.4
10–14	6.4	6.1	5.8	5.9	5.6
15–19	7.7	7.6	7.3	8.1	9.0
20–25	9.4	9.3	9.1	9.4	9.6
Total (0–25 yr)	18.4	18.7	18.6	18.1	18.1

deaths (73%).³⁸ Discharged survivors had a higher 1-year mortality than patients without serious illnesses. These findings highlight the risk of death for children with serious illness and why engagement with palliative care would be beneficial.

Infants and patients with a neurological or otherwise specified diagnosis were at the highest risk of instability. Infants were the largest group of patients with serious illness in our study, and also the most complex to analyze. Understanding the clinical trajectory of infants with serious illnesses presents challenges as they may be very ill in the neonatal period but then go on to have good outcomes. We noted that, after infancy, there was a decline in hospital-linked cases until adolescence and early adulthood. We hypothesize that this is because of new onset of conditions that are more common in older individuals (e.g., Hodgkin lymphoma) and deterioration from childhood conditions that led to a hospital admission (e.g., palliated congenital heart disease).

Future research could follow infants, children, youth and young adults with serious illnesses over time to better understand their individual health trajectories and movement through outpatient services when there is no hospital admission. In addition, future research should include indicators of the burden on the health care system and medical complexity to inform allocation and service planning.

Limitations

We focused on infants, children, youth and young adults who needed hospital inpatient care during a given year; there are likely those living with health conditions of interest who were not captured because they did not have an inpatient admission related to their serious illness in any of the study years. Outpatient data might describe infants, children, youth and young adults who are less fragile, but outpatient coding is not considered to be uniform or reliable enough for our project. This, combined with limited capture of secondary diagnoses, means the findings may represent an underestimation of the number of infants, children, youth and young adults with serious illnesses, but this does not affect the conclusion that current palliative care capacity is likely not adequate. By assigning each study participant a single outcome variable per fiscal year, we have missed more granular details on periods of stability or instability that these patients experience. Collapsing clinical stages into a binary variable was necessary because of small numbers, but doing so obscured more subtle differences in severity levels. Lastly, our work focuses on the population at risk of dying young from a medical condition; it does not describe the mortality risk profile for all infants, children, youth and young adults, which also includes mental health conditions leading to suicide, risky behaviour-related deaths or accidents.

Table 4: Odds ratios (ORs) for risk of instability among infants, children, youth and young adults who had a serious illnesses code recorded during a hospital admission in British Columbia*

Variable	Univariable model		Multivariable model	
	OR (95% CI)	p value	Adjusted OR (95% CI)	p value
Sex		0.81		0.61
Female	Ref.		Ref.	
Male	1.01 (0.94–1.08)		1.02 (0.95–1.10)	
Age group, yr		< 0.01		< 0.01
< 1	5.03 (4.57–5.54)		6.59 (5.97–7.29)	
1–4	Ref.		Ref.	
5–9	2.00 (1.71–2.34)		0.96 (0.82–1.13)	
10–14	2.11 (1.80–2.46)		0.99 (0.84–1.16)	
15–19	2.58 (2.26–2.94)		1.18 (1.03–1.35)	
20–25	2.85 (2.54–3.19)		1.25 (1.10–1.42)	
Socioeconomic status†		0.05		0.20
Missing	1.03 (0.79–1.35)		1.04 (0.78–1.38)	
1 (lowest income group)	1.14 (1.02–1.27)		1.10 (0.98–1.23)	
2	1.00 (0.90–1.12)		1.00 (0.89–1.12)	
3	0.96 (0.86–1.08)		0.98 (0.87–1.10)	
4	1.06 (0.95–1.19)		1.09 (0.97–1.22)	
5 (highest income group)	Ref.		Ref.	
Taxonomic unit		< 0.01		< 0.01
Oncology	Ref.		Ref.	
Perinatal	0.61 (0.55–0.67)		0.26 (0.23–0.30)	
Congenital	1.16 (1.04–1.30)		0.78 (0.68–0.88)	
Neurology	1.45 (1.23–1.71)		1.43 (1.21–1.70)	
Metabolic	1.20 (0.87–1.65)		0.98 (0.70–1.36)	
Otherwise specified‡	1.72 (1.55–1.91)		1.55 (1.39–1.73)	

*Models used 39348 observations (4198 events) from 11280 patients.
†Based on neighbourhood income quintiles.
‡Otherwise specified includes hematology, genitourinary, respiratory, gastrointestinal, circulatory, other and multiple diagnoses.

Conclusion

The present provision of palliative care for infants, children, youth and young adults in BC needs to expand to ensure access for all of those living with serious illnesses and not yet receiving pediatric palliative care, with a special focus on infants and other subpopulations with high risk of instability. A follow-up cohort analysis could explore the larger population of infants, children, youth and young adults who might be living with serious illnesses, but without frequent hospital admissions.

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Data sharing: The data that support the findings of this study are approved for use by data stewards and accessed through a process managed by Population Data BC. The data sets used for this study will be archived, and requests for access to them in the context of verification of study findings can be made to PopData (https://www.popdata.bc.ca/data_access). The authors are not permitted to share the research extract used in this analysis with other researchers, but the same data sets are accessible via Population Data BC.

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Disclaimer: Access to data provided by the data stewards is subject to approval but can be requested for research projects through the data stewards or their designated service providers. All inferences, opinions and conclusions drawn in this publication are those of the authors, and do not reflect the opinions or policies of the data stewards.

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