

# Children's End-of-Life Health Care Use and Cost

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abstract

**BACKGROUND AND OBJECTIVES:** Health care use and cost for children at the end of life is not well documented across the multiple sectors where children receive care. The study objective was to examine demographics, location, cause of death, and health care use and costs over the last year of life for children aged 1 month to 19 years who died in Ontario, Canada.

**METHODS:** We conducted a population-based retrospective cohort study using administrative databases to determine the characteristics of and health care costs by age group and cause of death over a 3-year period from 2010 to 2013.

**RESULTS:** In our cohort of 1620 children, 41.6% died of a chronic disease with wide variation across age groups. The mean health care cost over the last year of life was \$78 332 (Canadian) with a median of \$18 450, reflecting the impact of high-cost decedents. The mean costs for children with chronic or perinatal/congenital illnesses nearly tripled over the last 4 months of life. The majority of costs (67.0%) were incurred in acute care settings, with 88.0% of children with a perinatal/congenital illness and 79.7% with a chronic illness dying in acute care. Only 33.4% of children received home care in the last year of life.

**CONCLUSIONS:** Children in Ontario receive the majority of their end-of-life care in acute care settings at a high cost to the health care system. Initiatives to optimize care should focus on early discussion of the goals of care and assessment of whether the care provided fits with these goals.

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Dr Widger conceptualized and designed the study, interpreted the data, and drafted the initial manuscript; Dr Seow conceptualized and designed the study, interpreted the data, and reviewed and revised the manuscript; Dr Rapoport interpreted the data and reviewed and revised the manuscript; Mr Chalifoux conducted data analysis and reviewed and revised the manuscript; Dr Tanuseputro conceptualized and designed the study, carried out the initial analyses, interpreted the data, and reviewed and revised the manuscript, and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

**DOI:** 10.1542/peds.2016-2956

Accepted for publication Jan 17, 2017

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PEDIATRICS (ISSN Numbers: Print, 0031-4005; Online, 1098-4275).

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**FINANCIAL DISCLOSURE:** The authors have indicated they have no financial relationships relevant to the article to disclose.

**WHAT'S KNOWN ON THIS SUBJECT:** Research suggests that children's end-of-life care is more resource-intensive than that of adults, but previous research has primarily focused on the select group of children who receive Medicaid rather than the full population.

**WHAT THIS STUDY ADDS:** In a population-based sample, the vast majority of children with chronic or perinatal/congenital illnesses receive their end-of-life care in acute care settings at a high cost to the health care system.

**To cite:** Widger K, Seow H, Rapoport A, et al. Children's End-of-Life Health Care Use and Cost. *Pediatrics*. 2017;139(4):e20162956

Given the aging population and skyrocketing health care expenditures, attention has focused on health care use and cost in the last year of life. Although the number of children who die is small relative to adults, examination of health care usage patterns and the associated costs for children may reveal unique patient characteristics, needs, and opportunities to optimize service use and costs at the end of life. The European Association for Palliative Care Taskforce for Palliative Care in Children outlined the lack of information specific to children and recommended additional research be implemented in this area, with attention to the cost of all hospital, hospice, and home care medical staff and caregivers.<sup>1</sup>

Research suggests that children's end-of-life care is more resource intensive than that of adults, with estimated Medicaid expenditures in the last year of life totaling \$62 000 to \$110 000 US dollars, compared with \$28 000 US dollars for adults.<sup>2,3</sup> More specifically, for children with complex chronic conditions receiving Medicaid, the total annual cost per child averaged \$82 000 US dollars, with the vast majority spent on inpatient services with little use of hospice and home care.<sup>4</sup> A significant limitation of this research is that less than one-third of deceased children receive Medicaid benefits.<sup>3</sup> In addition, these studies were conducted before the passage of the Patient Protection and Affordable Care Act, when patients were allowed to take advantage of hospice benefits while still pursuing curative treatments.<sup>5</sup> Before this time, parents may have waived hospice benefits to continue with curative treatments. Consequently, children included in earlier research were likely different from the larger population of children who died at that time.

Because of universal health care coverage in Canada, health care expenditures across a range of

health sectors can be tracked for the entire population of each province by using administrative databases. To date, Canadian research has tended to focus exclusively on adult populations<sup>6–8</sup> or wide ranges within 1 age group (ie, ages 0–44 years).<sup>9</sup> One study focused on children and young adults (birth to 24 years) with life-threatening conditions found multiple and lengthy hospitalizations over the last year of life; however, costs were not examined.<sup>10</sup>

About 3300 children age  $\leq 19$  years die each year in Canada. About one-third of these deaths occur in the province of Ontario,<sup>11</sup> making it an ideal province to study to address gaps in the current literature.

## METHODS

We conducted a population-based retrospective cohort study using administrative data to examine demographics, diagnosis, location of death, and health care use and costs incurred by decedents age  $\leq 19$  years in the last year of life. By using encrypted health card numbers as unique identifiers, records were linked across relevant administrative databases. This study was approved by the research ethics board at the Institute for Clinical Evaluative Sciences, Sunnybrook Health Sciences Centre, and the Ottawa Hospital Research Institute. Written consent was not obtained because data were deidentified and anonymized.

## Cohort

Children who died in Ontario, Canada during a 3-year period from April 1, 2010 to March 31, 2013 were included. Age at the time of death was used to determine eligibility. Infants  $< 30$  days of age at the time of death were excluded ( $n = 2463$ ) because the majority did not have health card numbers to facilitate data linkages, resulting in large amounts of missing data.

## Data Sources

Eligible children were identified and demographic information was collected by using the Ontario Registered Persons Database, and health care use was determined by using the following databases (described elsewhere<sup>12</sup>): Continuing Care Reporting System; Home Care Database; Resident Assessment Instrument-Home Care; Canadian Institute for Health Information-Discharge Abstract Database; National Ambulatory Care Reporting System; Ontario Health Insurance Plan Claims Database; and Assistive Devices Program.

## Measures

### Demographics

Age categories were based on those used by Statistics Canada except for the youngest age group, where infants age  $\leq 30$  days were excluded. Age categories were 31 days to 1 year, 1 to 4 years, 5 to 9 years, 10 to 14 years, and 15 to 19 years. Statistics Canada census data and postal codes were used to determine income and rurality, following well-established methods.<sup>13,14</sup>

### Cause of Death

We created 4 broad categories of diseases based on those used by Knapp and colleagues<sup>15</sup> and the *International Classification of Disease, Tenth Revision (ICD-10)*<sup>16</sup>: (1) perinatal/congenital causes of death, which includes *ICD-10* chapters 15 to 17 (eg, conditions related to pregnancy or that began in the perinatal period, congenital malformations, and chromosomal anomalies); (2) chronic causes of death, which includes *ICD-10* chapters 1 to 14 (eg, infectious diseases, cancer, and disorders of the organ, circulatory, and nervous systems); (3) external causes of death, which includes *ICD-10* chapters 19 to 21 (eg, accidents, assault, drowning, and complications of medical care); and (4) other causes

of death, which includes *ICD-10* chapter 18 (eg, sudden infant death syndrome, unexplained deaths, and deaths associated with abnormal clinical and laboratory findings).

### Health Care–Related Variables

The location of death was categorized into 4 groups: (1) the ICU; (2) an institution, but outside of the ICU; (3) the emergency department (ED); or (4) a noninstitutional setting (eg, at home, in the sole pediatric freestanding hospice in the province during the study period, or before arrival to the ED [ie, after a motor vehicle accident or suicide]). We focused on the following 5 care settings: (1) acute care (the ICU and any acute care unit); (2) the ED; (3) complex continuing care (defined in Ontario as continuing, medically complex, and specialized services provided in hospitals for those with a chronic illness)<sup>17</sup>; (4) rehabilitation; and (5) home. The mean and median number of days spent in each setting was recorded for both the last 30 and 90 days of life. Health care use and cost were assessed over the last year of life in 3 sectors: (1) continuing care (ie, complex continuing care, home care, and rehabilitation); (2) acute care (ie, inpatient without ICU admission, inpatient with  $\geq 1$  ICU admission, and ED); and (3) outpatient care (ie, outpatient clinics, physician services, nonphysician services). In contrast to “hospice care” in the United States, pediatric hospices in Canada are physical buildings where expert pediatric palliative care (PPC) teams provide respite, symptom management, and end-of-life care. Admission and discharges to pediatric hospices are currently not included in administrative databases, thus hospice could not be included as a care setting or specific component of health care use. Physician services account for some costs in this setting, although other costs are primarily paid through philanthropic support and therefore are not fully included

in our analysis. Other costs typically associated with hospice care in the United States are reflected in home care costs in our study.

### Statistical Analysis

Data were stratified by age group and cause of death and summarized by using proportions or means. Multivariable analysis was undertaken by using logistic regression to examine the location of death (ICU or ED versus other locations) based on the following covariates: age, income, rurality, and cause of death.

To analyze cost data, all records of health care use paid for by the provincial Ministry of Health and Long Term Care in the last year of life were retrieved. The costs associated with each record for each health sector and each cause of death were estimated by using costing methods described elsewhere in detail.<sup>18</sup> A payer (Ministry of Health and Long Term Care) costing perspective was taken by using person-level health care expenditures that account for health care use and cost information per use. All costs were expressed in 2013 Canadian dollars, and past costs were inflated by using the health care–specific yearly Consumer Price Index reported by Statistics Canada. For cost data, we calculated means and medians to facilitate comparison with other studies reporting means and to better represent data skewed by the small number of high-cost users. We also examined mean costs by month before death and cause of death.

All statistical tests were two-tailed, and  $P < .05$  was used to determine statistical significance. We used SAS version 9.3 (SAS Institute, Inc, Cary, NC) for all analyses.

## RESULTS

### Cohort Demographics

During our 3-year study period, 1620 children age 1 month to 19 years died

in Ontario, Canada. More boys than girls (969 vs 651) died across the sample, with the largest proportion of deaths (37.6%) occurring in the 15- to 19-year-old age group (Table 1). The largest proportion of children were diagnosed with a chronic disease (41.6%), with wide variation across age groups (Table 1).

### Location of Care and Death

The majority of children (75.9%) died in an institution, including 35.8% in the ICU and 30.9% in the ED (Table 2). The location of death was generally reflective of the underlying diagnosis; the highest portion of deaths from perinatal/congenital illnesses occurred in the ICU (62.0%), whereas the highest proportion of deaths from external causes occurred in the ED or ICU (65.3%). Children with chronic illnesses also tended to die more often in an ICU setting (40.8%), whereas a small proportion died outside of an institution (20.3%).

Regardless of the cause of death, children received the most care in acute care settings over the last 30 (mean, 6.7 days) and 90 days (mean, 14.6 days) of life (Table 2). Complex continuing care and the ED had the next highest mean number of days, with little use of home care in any disease group.

A smaller sample of 1344 was used in multivariable analysis due to missing data for  $\geq 1$  covariates, particularly in the youngest age group. Age and cause of death were significant in the odds of dying in the ICU or ED compared with other locations (Table 3). Compared with 15- to 19-year-old children, infants  $< 1$  year of age had  $> 4$  times the odds of dying in the ICU or ED (odds ratio [OR] = 4.44; 95% confidence interval [CI] = 2.64–7.45), and children aged 1 to 4 years had  $> 3$  times the odds (OR = 3.34, 95% CI = 2.34–4.78) and those aged 10 to 14 years had over twice the odds (OR = 2.06; 95% CI = 1.45–2.92) of dying in those locations. Children with a cause of

**TABLE 1** Cohort Demographics by Age (*n* = 1620)

	Age of Decedent					Total	<i>P</i>
	31 d–1 y <i>n</i> = 385	1–4 y <i>n</i> = 259	5–9 y <i>n</i> = 156	10–14 y <i>n</i> = 211	15–19 y <i>n</i> = 609		
Sex, <i>n</i> (%)							
Girl	158 (41.0)	105 (40.5)	73 (46.8)	98 (46.4)	217 (35.6)	651 (40.2)	.02
Boy	227 (59.0)	154 (59.5)	83 (53.2)	113 (53.6)	392 (64.4)	969 (59.8)	
Income quintile, <i>n</i> (%)							
Lowest	49 (12.7)	64 (24.6)	44 (28.2)	40 (18.6)	136 (22.3)	333 (20.6)	<.0001
Low	26 (6.8)	48 (18.4)	22 (14.1)	46 (21.4)	120 (19.7)	262 (16.2)	
Middle	27 (7.0)	49 (18.8)	24 (15.4)	46 (21.4)	123 (20.2)	269 (16.6)	
High	25 (6.5)	52 (20.0)	36 (23.1)	30–35 (15.1)	102 (16.8)	246 (15.2)	
Highest	16 (4.2)	40–45 (16.3)	30 (19.2)	46 (21.4)	120 (19.7)	253 (15.6)	
Missing	242 (62.9)	0–10 (1.9)	0 (0)	0–10 (2.3)	8 (1.3)	257 (15.9)	
Rurality, <i>n</i> (%)							
Urban	126 (32.7)	216 (82.0)	132 (84.6)	165 (78.2)	485 (79.2)	1124 (69.4)	<.0001
Rural	20 (5.2)	40–45 (16.1)	24 (15.4)	46 (21.8)	120–125 (20.0)	255 (15.7)	
Missing	239 (62.1)	0–10 (1.9)	0 (0)	0 (0)	0–10 (0.8)	241 (14.9)	
Cause of death, <i>n</i> (%)							
Perinatal/ congenital	149 (38.5)	32 (12.1)	14 (9.1)	18 (8.5)	21 (3.5)	234 (14.4)	<.0001
Chronic	118 (30.5)	139 (52.8)	98 (63.6)	122 (57.3)	197 (32.4)	674 (41.6)	
External	23 (5.9)	70 (26.6)	32 (20.8)	63 (29.6)	365 (59.9)	553 (34.1)	
Other	90–95 (23.9)	15–20 (6.6)	0–10 (3.3)	0–10 (2.4)	18 (3.0)	137 (8.5)	
Missing	0–10 (1.3)	0–10 (1.9)	0–10 (3.3)	0–10 (2.4)	8 (1.3)	22 (1.4)	

Numbers <5 are not reported in any cell due to privacy issues. Ranges are included for at least 1 other cell in the corresponding row and column so totals can be reported. Proportions reported for each range represent the midpoint of the range.

**TABLE 2** Care Setting and Location of Death, by Cause of Death (*n* = 1620)

	Perinatal / Congenital <i>n</i> = 234	Chronic <i>n</i> = 674	External <i>n</i> = 553	Other <i>n</i> = 137	Missing <i>n</i> = 22	Total
Care setting in last 30 d of life (mean/median, d)						
Acute care	16.2/20.0	8.9/2.0	1.7/0	1.1/1.2	0/0	6.7/0
ED	0.2/0	0.3/0	0.2/0	0.1/0.2	0/0	0.2/0
Complex continuing care	0/0	0.1/0	0/0	0/0	0/0	0/0
Rehabilitation	0/0	0/0	0/0	0/0	0/0	0/0
Home care	0/0	0/0	0/0	0/0.1	0/0	0/0
Total use	16.4/21.0	9.3/3.0	1.9/0	1.3/1.5	0/0	7.0/0
Care setting in last 90 d of life (mean/median, d)						
Acute care	35.6/33.0	19.7/5.0	2.5/0	4.3/0	0/0	14.6/0
ED	0.5/0	0.6/0	0.4/0	0.3/0.0	0/0	0.5/0
Complex continuing care	0/0	0.1/0	0/0	0/0	0/0	0.1/0
Rehabilitation	0/0	0/0	0/0	0/0	0/0	0/0
Home care	0/0	0/0	0/0	0/0.1	0/0	0/0
Total use	36.1/33.0	20.5/7.0	3.0/0	4.6/1.0	0/0	15.1/1.0
Location of death, <i>n</i> (%) <sup>*</sup>						
ICU	145 (62.0)	275 (40.8)	154 (27.9)	0–10 (3.5)	0–10 (15.4)	580 (35.8)
ED	38 (16.2)	152 (22.6)	207 (37.4)	104 (73.5)	0 (0)	501 (30.9)
Non-ICU institution	23 (9.8)	110 (16.3)	14 (2.5)	0–10 (3.5)	0–10 (15.4)	148 (9.1)
Noninstitution	28 (12.0)	137 (20.3)	178 (32.2)	25–30 (19.4)	20–25 (69.2)	391 (24.1)

Numbers <5 are not reported in any cell due to privacy issues. Ranges are included for at least 1 other cell in the corresponding row and column so totals can be reported. Proportions reported for each range represent the midpoint of the range.

\* *P* < .0001

death due to a chronic condition, compared with an external cause, had almost 40% lower odds of dying in the ICU or ED (OR = 0.60; 95% CI = 0.46–0.79).

### Health Care Use and Cost

The mean cost of health care in the last year of life for children was \$78 332 (Canadian) with a total cost

of \$124 million annually, and 75% of these costs were incurred in the acute care sector. The mean costs were consistent in each of the 3 fiscal years (\$78 293 in 2010, \$76 915 in 2011,

**TABLE 3** Odds of Dying in the ICU or ED Versus Other Locations

	OR <sup>a</sup>	95% CI
Age		
31 d–1 y	4.44	2.64–7.45
1–4 y	3.34	2.34–4.78
5–9 y	1.40	0.96–2.05
10–14 y	2.06	1.45–2.92
15–19 y	1.0 (reference)	
Sex		
Boy	1.13	0.89–1.44
Girl	1.0 (reference)	
Income quintile		
Lowest	1.61	1.13–2.30
Low	1.31	0.91–1.88
Middle	1.38	0.95–1.99
High	1.80	1.23–2.64
Highest	1.0 (reference)	
Rurality		
Rural	1.16	0.86–1.58
Urban	1.0 (reference)	
Cause of death		
Perinatal	0.84	0.53–1.35
Chronic	0.60	0.46–0.79
External	1.0 (reference)	
Other	0.94	0.49–1.77

Analysis is based on a sample of 1344 due to missing data on one or more covariates.

<sup>a</sup> OR >1 indicates more likely to die in ICU/ED.

and \$79 962 in 2012). The median total cost was lower at \$18 450, reflecting the impact of some high-cost decedents. Table 4 reports the number of children with at least 1 record in at least 1 health sector and the associated mean and median cost among users, by diagnosis category.

The highest median total costs were for children in the perinatal/congenital disease category (\$103 472; quarter [Q]1, \$45 288; Q3, \$218 889) followed by chronic diseases (\$63 101; Q1, \$14 479; Q3, \$154 116) (Table 4). Across all disease groups, the highest mean hospital costs were among those with at least 1 ICU visit (43.7% of decedents) in the last year of life at \$116 630 (median, \$60 843) (Table 4). An additional 23.4% were admitted to hospital but did not receive care in the ICU in the final year of life, with a mean cost of \$29 516 (median, \$6882). The majority of children (80.0%) had at least 1 ED visit, but at relatively low cost (mean \$1128). In contrast, only 33.4% received home care at a mean annual cost of \$24 448. A large proportion of decedents in their last year of life had at least 1 physician

visit (98.5%) with lower proportions having a drug/device paid for by the provincial insurance (32.9%) or a laboratory test (27.6%) with relatively small average annual costs. Medians for all sectors were lower than means, again reflecting high-cost users, which skew the data positively.

Figure 1 shows the mean costs per child over the last year of life by month before death and by diagnosis. The mean cost in the last month of life was \$23 963, with the highest mean costs for children with perinatal/congenital illness (\$48 476), followed by those with chronic illness (\$30 028). The mean cost for children with perinatal/congenital illnesses nearly doubled between 12 and 5 months before death, but then increased another 2.5 times over the last 4 months of life. Children with chronic illness showed a similar pattern, with mean costs tripling over the last 4 months of life.

## DISCUSSION

Our study is the first population-based study to describe both the use and

cost of health care services across a multitude of sectors at the end of life for children. Despite a high number of sudden deaths due to external causes, where interaction with the health care system was short, the mean health care costs over the last year of life for children was considerably higher than for adults in the same province (\$78 332 vs \$53 661).<sup>12</sup> These high costs are particularly true for those <10 years of age and are driven by deaths due to perinatal/congenital and chronic conditions. The vast majority (67%) of costs for children are incurred in acute care settings, whereas the proportion of acute care costs among adults at the end of life is only 43%.<sup>12</sup> In children, costs increased more dramatically 5 months before death, whereas in adults, a similar increase began at 3 months before death.<sup>12</sup>

A large proportion of children with perinatal/congenital (88.0%) or chronic conditions (79.7%) died in an acute care setting. These children also spent much of the last 30 and 90 days of life in hospital. End-of-life care and death at home are the preference of 75% of Canadian adults<sup>19</sup>; however, there is less evidence that parents prefer home as the location of care and death for children.<sup>20</sup> For parents of children who died of cancer cared for at a single center in Ontario, 70.2% preferred care over the last month of life at home, 15.3% in the hospital, and 6.9% in a freestanding hospice, whereas 23.0% preferred the hospital for the actual location of death.<sup>21</sup> At the time of the study, no freestanding pediatric hospice was available for these families, perhaps partially explaining the low level of preference for that location. Even for children in our study with chronic diseases, <60% used home care in the last 30 days of life. We are unable to determine if low home care use is due to lack of available services or a lack of planning and discussion about end-of-life care; however, high acute care costs during the last month of life for children with chronic conditions suggests that more families might have benefited from

**TABLE 4** Use and Cost by Sector and Cause of Death in the Last Year of Life

	Perinatal			Chronic			External			Other			Total <sup>a</sup>		
	Users, n (%)	Mean, \$	Median, \$ (Q1-Q3)	Users, n (%)	Mean, \$	Median, \$ (Q1-Q3)	Users, n (%)	Mean, \$	Median, \$ (Q1-Q3)	Users, n (%)	Mean, \$	Median, \$ (Q1-Q3)	Users, n (%)	Mean, \$	Median, \$ (Q1-Q3)
Continuing care sectors															
Complex continuing care	0	0	0	10-15 (1.9)	10699	6640 (2157-19673)	b	b	b	0	0	0	10-15 (0.8)	9923	2219 (2157-19673)
Home care	110 (47.0)	217712	4388 (1818-17304)	389 (57.9)	25729	7996 (3102-19330)	19 (3.6)	15067	1843 (914-10208)	10 (27.8)	24249	3748 (1462-25013)	529 (33.4)	24448	6971 (2414-18443)
Rehabilitation	0	0	0	0-10 (0.7)	3909	3909 (198-7620)	0	0	0	0	0	0	0-10 (0.3)	3909	3909 (198-7620)
Acute care sectors															
Inpatient without ICU admission	30 (12.8)	39498	11284 (5661-23708)	188 (28.0)	47016	18621 (6344-42724)	81 (15.3)	8522	5231 (2455-7788)	71 (52.2)	2911	1288 (769-1831)	370 (23.4)	29516	6882 (2071-22525)
Inpatient with ≥1 ICU admission	187 (80.0)	168718	99163 (56656-226225)	345 (51.3)	127574	71209 (23330-181488)	136 (25.7)	29668	13124 (4250-31231)	24 (17.6)	46258	23202 (6228-65822)	692 (43.7)	116631	60843 (15213-152393)
ED	130 (55.6)	1682	1174 (660-2026)	587 (87.4)	1255	926 (548-1530)	434 (81.9)	945	696 (367-1274)	116 (85.3)	545	363 (161-697)	1267 (80.0)	1128	803 (416-1435)
Outpatient care sectors															
Outpatient clinics	10-15 (5.3)	8321	2123 (1204-3451)	163 (24.2)	17035	12595 (2747-24166)	29 (5.5)	1905	1358 (848-1722)	0-10 (3.7)	1608	1920 (826-2078)	206 (13.0)	14215	9244 (1555-20635)
Physician services	232 (99.1)	14954	10155 (4842-19006)	668 (99.4)	10867	7217 (2259-14971)	515 (97.2)	2601	912 (300-3502)	134 (98.5)	1300	574 (297-1345)	1560 (98.5)	8068	3499 (664-10687)
Nonphysician services (OHIP)	19 (8.1)	69	66 (44-71)	152 (22.6)	73	45 (44-68)	131 (24.7)	134	44 (44-45)	8 (5.9)	45	44 (44-45)	313 (19.8)	97	45 (44-66)
Laboratory (OHIP)	34 (14.5)	79	47 (22-83)	236 (35.1)	122	66 (28-137)	152 (28.7)	89	58 (33-116)	15-20 (12.9)	63	54 (22-83)	435-440 (27.6)	105	60 (28-129)
Drugs/devices	83 (35.5)	4343	1585 (162-6375)	348 (51.8)	5444	2547 (517-6630)	71 (13.4)	1101	118 (45-647)	19 (14.0)	2445	37 (13-1296)	521 (32.9)	4567	1585 (204-5928)
Total cost	234	167838	103472 (45288-218889)	672	112623	63101 (14479-154116)	530	13071	1963 (638-10407)	136	13599	2037 (1049-5863)	1584	78332	18450 (1744-98121)

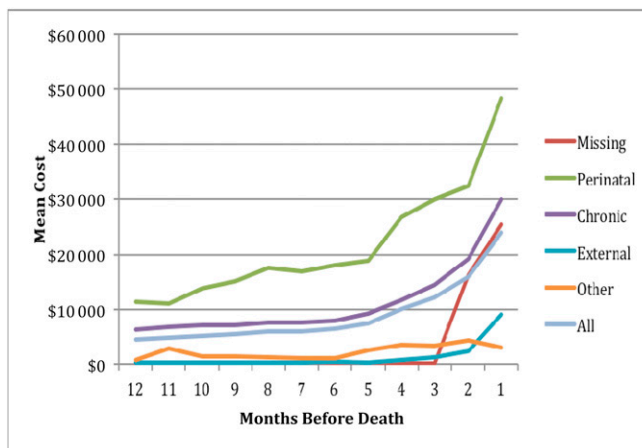
All dollar values are in 2013 Canadian dollars. Numbers <5 are not reported in any cell due to privacy issues. Ranges are included for at least 1 other cell in the corresponding row and column so totals can be reported. Proportions reported for each range represent the midpoint of the range. OHIP, Ontario Health Insurance Plan.

<sup>a</sup> An additional 12 users with missing cause of death are included in the totals, but could not be reported separately due to small numbers in each cell.

<sup>b</sup> Only 1 user; so mean, median, and Q1-Q3 are equivalent and could not be reported due to privacy issues.

home care. In a study of children with a wide variety of diagnoses who received care from a PPC team associated with a well-established freestanding hospice, the location of death was evenly divided among hospital, home, and hospice,<sup>22</sup> suggesting that when appropriate supports are available in each location, families have greater choice and fewer deaths happen in acute care settings.

Involvement of specialized PPC teams may be one method for reducing the high cost of end-of-life care while also improving quality, particularly for children whose death is foreseeable. Involvement of PPC teams is associated with shorter lengths of hospital stay, reduced aggressive interventions and deaths in the ICU,<sup>23-25</sup> increased likelihood of death at home or a freestanding hospice,<sup>23,26,27</sup> improved communication about the goals of care,<sup>28</sup> and increased quality of life.<sup>28</sup> However, a recent systematic review found conflicting results with 6 of 8 included studies indicating reduced overall costs when care was provided by a PPC team, but 2 studies finding an increase in costs.<sup>29</sup> Most included studies, plus a more recent analysis of costs associated with specialist PPC services, focused only on hospital-based costs rather than including costs that may have shifted to other settings, such as home care and hospice.<sup>29,30</sup> Because of universal health care coverage in Canada, we were able to track expenditures across multiple sectors, including home care; however, the costs associated with care in a freestanding hospice paid through philanthropic support were not included in our analysis. Unfortunately, we were also unable to determine which children received specialized PPC services due to nonspecific billing codes used by these teams. Additional work is needed to track the cost and use of specialist PPC services and hospices at a population level because the availability of these services and facilities continues to grow in Canada.<sup>31</sup>



**FIGURE 1**

Mean costs in the last year of life by month and cause of death. Note: All dollar values are in 2013 Canadian dollars.

Our findings are potentially generalizable to other countries with similar health systems (eg, England and Norway); however, differences in end-of-life care practices have been demonstrated across developed countries.<sup>32</sup> Due to a lack of health card numbers to facilitate linkages across databases, we excluded 2463 infants <1 month of age from our analysis. This group of children likely received high-intensity care over short time frames, which may have additionally increased the mean and median costs of the youngest age group in our study if their data were included. This group may represent additional opportunities to optimize care. The majority of rehabilitation services for children in Ontario are funded through the Ministry of Children and Youth Services rather than through the Ministry of Health, therefore, not all associated rehabilitation costs were included in our analysis. Given that these services are provided to 74 000 children with moderate to severe disabilities in Ontario each year,<sup>33</sup> it is likely that some children received these services at unknown additional cost. Similarly, prescription drug costs are not fully covered by provincial health insurance and therefore are likely underrepresented in our analysis.

## CONCLUSIONS

Children currently receive the majority of their end-of-life care in acute care settings at a high cost to the health care system. Although some costs are appropriate and unavoidable, there are likely opportunities to optimize costs in each setting. This study provides important information about children's health care use and cost at the end of life at a population level, but does not speak to the quality of care or the decision-making process around health care use. Particularly for children with perinatal/congenital or chronic conditions, additional research is needed to assess whether the goals of care are appropriately discussed early in the disease process and whether the care provided fits with these goals. In addition, research is needed to assess the role of specialized PPC services and hospices in optimizing care and potentially reducing costs.

## ABBREVIATIONS

CI: confidence interval  
 ED: emergency department  
 ICD-10: International Classification of Diseases, Tenth Revision  
 OR: odds ratio  
 PPC: pediatric palliative care  
 Q: quarter

**FUNDING:** This work was supported by a research grant from the Ontario Ministry of Health and Long Term Care (MOHLTC) to the Health System Performance Research Network (HSPRN grant 06034). This work was also supported by the Institute for Clinical Evaluative Sciences, which is funded by an annual grant from the Ontario MOHLTC. Dr Widger was supported by a Career Development Award from the Canadian Child Health Clinician Scientist Program and the Canadian Institutes for Health Research Strategy for Patient-Oriented Research. The views expressed in this paper are the views of the authors and do not necessarily reflect those of the funder. The funders had no influence on the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript.

**POTENTIAL CONFLICT OF INTEREST:** The authors have indicated they have no potential conflicts of interest to disclose.

## REFERENCES

1. European Association of Palliative Care Taskforce for Palliative Care in Children; Fondazione Maruzza Lefebvre D'ovidio Onlus. Palliative care for infants, children and young people: the facts. Available at: [http://www.palliative.lv/wp-content/uploads/2013/01/The\\_Fact.pdf](http://www.palliative.lv/wp-content/uploads/2013/01/The_Fact.pdf). Accessed February 11, 2017
2. Emanuel EJ, Ash A, Yu W, et al. Managed care, hospice use, site of death, and medical expenditures in the last year of life. *Arch Intern Med*. 2002;162(15):1722–1728
3. Knapp CA, Thompson LA, Vogel WB, Madden VL, Shenkman EA. Developing a pediatric palliative care program: addressing the lack of baseline expenditure information. *Am J Hosp Palliat Care*. 2009;26(1):40–46
4. Lindley LG, Lyon ME. A profile of children with complex chronic conditions at end of life among Medicaid beneficiaries: implications for health care reform. *J Palliat Med*. 2013;16(11):1388–1393
5. National Hospice and Palliative Care Organization. Concurrent care for children. Available at: [www.nhpco.org/resources/concurrent-care-children](http://www.nhpco.org/resources/concurrent-care-children). Accessed August 21, 2016
6. Menec V, Lix L, Steinbach C, et al. Patterns of health care use and cost at the end of life. Available at: <http://mchp-appserv.cpe.umanitoba.ca/deliverablesList.html>. Accessed February 19, 2015
7. Hollander MJ, Tessaro A. Health care use at the end of life in Saskatchewan. Available at: [https://secure.cihi.ca/free\\_products/EOL\\_Report\\_Saskatchewan.pdf](https://secure.cihi.ca/free_products/EOL_Report_Saskatchewan.pdf). Accessed February 19, 2015
8. Canadian Institute for Health Information. Health care use at the end of life in Atlantic Canada. Available at: [https://secure.cihi.ca/free\\_products/end\\_of\\_life\\_2011\\_en.pdf](https://secure.cihi.ca/free_products/end_of_life_2011_en.pdf). Accessed February 19, 2015
9. Kuropatwa R. Health care use at the end of life in British Columbia. Available at: [https://secure.cihi.ca/free\\_products/EOL\\_Report\\_BC.pdf](https://secure.cihi.ca/free_products/EOL_Report_BC.pdf). Accessed February 19, 2015
10. Chavoshi N, Miller T, Siden H. Resource utilization among individuals dying of pediatric life-threatening diseases. *J Palliat Med*. 2013;16(10):1210–1214
11. Statistics Canada. Table 102-0503 - deaths, by age and sex, Canada, provinces and territories, annual (number). Available at: [www5.statcan.gc.ca/cansim/a26?lang=eng&id=1020503](http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1020503). Accessed February 18, 2015
12. Tanuseputro P, Wodchis WP, Fowler R, et al. The health care cost of dying: a population-based retrospective cohort study of the last year of life in Ontario, Canada. *PLoS One*. 2015;10(3):e0121759
13. Stephenson A, Hux J, Tullis E, Austin PC, Corey M, Ray J. Socioeconomic status and risk of hospitalization among individuals with cystic fibrosis in Ontario, Canada. *Pediatr Pulmonol*. 2011;46(4):376–384
14. Kralj B. Measuring rurality – RIO2008 BASIC: methodology and results. 2009. Available at: [www.eriectclairhin.on.ca/Page.aspx?id=11606](http://www.eriectclairhin.on.ca/Page.aspx?id=11606). Accessed February 11, 2016
15. Knapp CA, Shenkman EA, Marcu MI, Madden VL, Terza JV. Pediatric palliative care: describing hospice users and identifying factors that affect hospice expenditures. *J Palliat Med*. 2009;12(3):223–229
16. World Health Organization. *International Statistical Classification of Diseases and Related Health Problems. 10th Revision*. Geneva, Switzerland: WHO Press; 2010
17. Ontario Ministry of Health and Long-Term Care. Hospital chronic care co-payment/questions and answers. Available at: [www.health.gov.on.ca/en/public/publications/chronic/chronic.aspx](http://www.health.gov.on.ca/en/public/publications/chronic/chronic.aspx). Accessed February 18, 2015
18. Wodchis WP, Bushmeneva K, Nikitovic M, McKillop I; Health System Performance Research Network. Guidelines on person level cost using administrative databases in Ontario. Working paper series. Volume 1. Available at: [http://hsprn.ca/uploads/files/Guidelines\\_on\\_PersonLevel\\_Costing\\_May\\_2013.pdf](http://hsprn.ca/uploads/files/Guidelines_on_PersonLevel_Costing_May_2013.pdf). Accessed February 18, 2015
19. Harris/Decima; Canadian Hospice Palliative Care Association. What Canadians say: the way forward survey report. Available at: [www.hpcintegration.ca/resources/what-canadians-say.aspx](http://www.hpcintegration.ca/resources/what-canadians-say.aspx). Accessed February 18, 2015
20. Bluebond-Langner M, Beecham E, Candy B, Langner R, Jones L. Preferred place of death for children and young people with life-limiting and life-threatening conditions: a systematic review of the literature and recommendations for future inquiry and policy. *Palliat Med*. 2013;27(8):705–713
21. Kassam A, Skiadaresis J, Alexander S, Wolfe J. Parent and clinician preferences for location of end-of-life care: home, hospital or freestanding hospice? *Pediatr Blood Cancer*. 2014;61(5):859–864
22. Siden H, Miller M, Straatman L, Omesi L, Tucker T, Collins JJ. A report on location of death in paediatric palliative care between home, hospice and hospital. *Palliat Med*. 2008;22(7):831–834



23. Schmidt P, Otto M, Hechler T, Metzger S, Wolfe J, Zernikow B. Did increased availability of pediatric palliative care lead to improved palliative care outcomes in children with cancer? *J Palliat Med.* 2013;16(9):1034–1039
24. Gans D, Kominski G, Roby D, et al. Better outcomes, lower costs: palliative care program reduces stress, costs of care for children with life-threatening conditions. *Policy Brief UCLA Cent Health Policy Res.* 2012;PB2012-3:1–8
25. Keele L, Keenan HT, Sheetz J, Bratton SL. Differences in characteristics of dying children who receive and do not receive palliative care. *Pediatrics.* 2013;132(1):72–78
26. Fraser LK, Miller M, Draper ES, McKinney PA, Parslow RC; Paediatric Intensive Care Audit Network. Place of death and palliative care following discharge from paediatric intensive care units. *Arch Dis Child.* 2011;96(12):1195–1198
27. Wolff J, Robert R, Sommerer A, Volz-Fleckenstein M. Impact of a pediatric palliative care program. *Pediatr Blood Cancer.* 2010;54(2):279–283
28. Kassam A, Skiadaresis J, Alexander S, Wolfe J. Differences in end-of-life communication for children with advanced cancer who were referred to a palliative care team. *Pediatr Blood Cancer.* 2015;62(8):1409–1413
29. Conte T, Mitton C, Trenaman LM, Chavoshi N, Siden H. Effect of pediatric palliative care programs on health care resource utilization and costs among children with life-threatening conditions: a systematic review of comparative studies. *CMAJ Open.* 2015;3(1):E68–E75
30. Smith AG, Andrews S, Bratton SL, et al. Pediatric palliative care and inpatient hospital costs: a longitudinal cohort study. *Pediatrics.* 2015;135(4):694–700
31. Widger K, Davies D, Rapoport A, et al. Pediatric palliative care in Canada in 2012: a cross-sectional descriptive study. *CMAJ Open.* 2016;4(4):e562–e568
32. Bekelman JE, Halpern SD, Blankart CR, et al; International Consortium for End-of-Life Research (ICELR). Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA.* 2016;315(3):272–283
33. Ontario Ministry of Children and Youth Services. Children's rehabilitation services. Available at [www.children.gov.on.ca/htdocs/English/specialneeds/rehabilitation.aspx](http://www.children.gov.on.ca/htdocs/English/specialneeds/rehabilitation.aspx). Accessed August 20, 2016

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*Pediatrics* 2017;139;

DOI: 10.1542/peds.2016-2956 originally published online March 2, 2017;

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