

Original Article

General paediatric inpatient deaths over a 15-year period

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Abstract

Objective: To retrospectively review trends of general paediatric inpatient deaths at a tertiary care children's hospital over a 15-year period.

Methods: Data were collected for all patients who died on the general paediatric wards or paediatric intensive care unit (PICU) during 1998, 2005 or 2012 and had a 'general paediatric condition'—an underlying condition or diagnosis that would normally result in admission to a general paediatric ward. Data were related to: demographics, health services utilization, information about provision and orders related to cardiopulmonary resuscitation (CPR) at time of death and involvement of palliative care services.

Results: Eighty-five inpatients met inclusion criteria: 35 in 1998, 27 in 2005 and 23 in 2012. Nearly 95% of general paediatric patients who died in 1998 did so in the PICU, 59.3% in 2005 and 69.6% in 2012. The median age of death decreased from 3 years in 1998 to 2 years in 2012. The proportion of patients with 'no CPR' orders at time of death increased from 31.4% in 1998 to 87.0% in 2012. Similarly, the proportion of patients with palliative care team involvement prior to death increased from less than 10% in 1998 to 73.9% in 2012.

Conclusions: The absolute number of inpatient general paediatric deaths has decreased from 1998 to 2012 at this hospital. A larger proportion of these deaths are occurring on the general paediatric wards rather than in the PICU over time. 'No CPR' orders and palliative care consultations are becoming more prevalent in these patients prior to death.

Keywords: Child; Death; Inpatients; Intensive care units; Paediatrics; Palliative care.

There have been many medical advances in neonatal and critical care, which have resulted in improvement in the survival rates of infants and children with complex health problems. However, due to their medical fragility, there has concomitantly been an increase in the number of admissions for children with multiple chronic conditions (1,2). These children make up a significant proportion of nontraumatic paediatric deaths (3). Paediatric deaths usually occur in one of three locations: home, hospice or hospital (4). The majority of children and young adults with chronic complex health problems who die, do so in the hospital setting (5), with up to 85% of deaths occurring in the paediatric intensive care unit (PICU) (6).

Recent evidence has demonstrated a shifting pattern in the location of death of children with chronic complex conditions, with an increasing number of families choosing end-of-life care for their children outside of the hospital setting (7), and a greater proportion dying at home (8). There are three trends that may be contributing to this shift: 1) the increased prevalence of children living with life-threatening conditions, 2) the increased use of sophisticated technology in

the home for children at risk of death and 3) the availability of paediatric palliative care services in the community (8). To the best of our knowledge, there is no previous research examining whether shifts have occurred over time within the hospital setting, with respect to location of death (e.g., out of the PICU). In recent years, we have anecdotally noted an increasing number of children dying on the general paediatric wards (GPW) at our hospital. As such, we chose to examine the deaths of general paediatric inpatients over time to document whether a true shift has occurred and, if so, to identify possible trends that may help explain such a shift.

The purpose of this retrospective health record review was to compare groups of children who died from 'general paediatric conditions' (see definition below) on the GPW or in the PICU at the Hospital for Sick Children in the years 1998, 2005 and 2012. The guiding research questions were: 1) Has there been a shift in location of death for general paediatric inpatients within the hospital over time? 2) Have there been any changes in the demographic characteristics of general paediatric patients who have died

in different locations within the hospital (underlying condition, age, etc.)? 3) What are the resources being used by general paediatric patients who die in hospital?

METHODS

The Hospital for Sick Children is a 350-bed tertiary care children's hospital affiliated with the University of Toronto, Ontario. A decision was made to review deaths only after 1998 because of the availability of detailed electronic mortality data beginning in this calendar year; the year 2012 was chosen because it was the most recent calendar year for which complete information regarding inpatient deaths was available. The year 2005 represents the midway point within the range for which data were available. It was hoped that by examining changes over 7-year intervals, we might better appreciate how patterns have changed over time.

While traditional studies have looked at disease-specific mortality patterns (e.g., prematurity, cancer, heart disease and trauma), we pragmatically defined our study population based on usual location of care within our hospital. Children admitted to our institution on one of the four GPW, under the care of a Paediatric Generalist, include those with previously undiagnosed conditions, presumed infectious diseases and conditions affecting more than one organ system (e.g., genetic, metabolic and complex chronic conditions). Conversely, patients admitted with diagnoses of cancer; primary cardiac, renal or respiratory disease; trauma; transplant; surgical conditions; or those requiring intensive care would be admitted under the care of subspecialists on their specific wards.

Health records of all children who died on the GPW or the PICU during the calendar years 1998, 2005 or 2012 were included. Children who died in the PICU were included if they had an underlying 'general paediatric condition'—defined as a diagnosis that would normally result in admission to the GPW in our hospital, had the child not required intensive care support. Therefore, all children who died in the PICU as a result of cancer, cardiac disease and trauma were excluded a priori, as these are diagnoses that would not typically result in admission to the GPW in our institution. Where it was not obvious if the child's underlying condition met inclusion criteria, two investigators (J.N.F. and A.R.), who work on the GPW, reviewed the case to determine the eligibility for the study. Children whose records had been locked (unavailable for review), typically for medico-legal reasons, and children who had died at home were excluded.

Charts of patients who fulfilled inclusion criteria were accessed through both Health Records and Morbidity and Mortality records. Data elements collected included demographic information such as age at death, year of death and diagnoses. The International Classification of Disease-Tenth Revision System (ICD-10) was used to classify the underlying diagnoses (9). Health service data included length of stay of final admission, number of PICU admissions in the child's lifetime, total number of admissions to our hospital, the proportion of the child's life spent at our hospital and whether the palliative care team was involved in the patient's care. Information about the presence and timing of a 'no cardiopulmonary resuscitation' (no CPR) order prior to death and the provision of CPR at the time of death was also noted.

Comparisons were made among the children who died across the three time periods to explore trends in child demographics and the use of health services. Continuous variable data were tested for normality using visual inspection and the Shapiro–Wilk test. This testing indicated that none of these variables were normally distributed and, thus, were compared across years using the independent sample Kruskal–Wallis test (which is analogous to analysis of variance for normally distributed data). We report medians and the 25th and 75th percentiles for these variables. Categorical data were compared using chi-square tests. A *P* value of 0.05 was used to indicate statistical

significance. Ethics approval was granted by the Hospital for Sick Children's Research Ethics Board.

RESULTS

There were 171, 173 and 154 inpatient deaths at our institution in 1998, 2005 and 2012, respectively. A total of 85 deaths met the inclusion criteria: 35 in 1998, 27 in 2005 and 23 in 2012. Although median age at death declined over the three time points, it did not vary significantly by year: the median age at death was 3 years in 1998 (0.9 to 11.0), 3 years in 2005 (0.5 to 7.0) and 2 years in 2012 (0.3 to 7.0) (*P*=0.46).

The number of children with a primary diagnosis classified in each chapter was too small to report by year, without potentially compromising anonymity. The most common underlying diagnoses across all years combined were diseases of the nervous system (31.8%), diseases of the respiratory system (14.1%) and congenital malformations, deformations and chromosomal abnormalities (9.4%) (Table 1).

As shown in Table 2, there was a significant decrease in the number of patients dying in the PICU in comparison to the GPW from 1998 to the latter two time periods (*P*<0.01). In 1998, most of the general paediatric patients died in the PICU (94.3%), compared with 59.3% in 2005 and 69.6% in 2012 (there was no statistically significant difference between the last two time points).

There was an increase in the proportion of children who had a 'no CPR' order from 1998 to 2005 onward: 31.4% in 1998 compared with 88.9% and 87.0% in 2005 and 2012, respectively (*P*<0.01). Among patients with this order in place, the number of days from the 'no CPR' order until death also increased from 1998 to 2005 onward from a median of 0 days in 1998 (0.0 to 1.0) to 3.5 days in 2005 (1.0 to 10.5) and 4 days in 2012 (1.0 to 13.5) (*P*<0.01). In addition to the increased median number of days for a 'no CPR' order to be in place, the range between a 'no CPR' order until death also increased overtime: 0 to 11 days in 1998, 0 to 32 days in 2005 and 0 to 183 days in 2012. There was also a significant increase in the proportion of children who had consultations with the paediatric palliative care team from 1998 to 2005 onward (*P*<0.01). In 1998, less than 10% had consultations versus 70.4% in 2005 and 73.9% in 2012 (Table 2). There were no consistent differences found across the three time periods in health care utilization, including the number of admissions to the children's hospital or to the PICU over the entire lifetime or the last year of life, the proportion of days spent in the tertiary hospital over the lifetime or length of stay in hospital during final admission.

DISCUSSION

A trend toward fewer inpatient general paediatric deaths was noted over three time points in a span of 15 years, consistent with the overall reduction in paediatric mortality, from all causes, in Canada (10). Although the PICU remains the most prevalent location of death among all children (11,12), between 1998 and 2005, we observed a significant increase in the proportion of deaths resulting from general paediatric conditions that occurred on the GPW. This increase was sustained in 2012. In 1998, only 5.7% of general paediatric inpatient deaths occurred on the GPW; in contrast, by 2005, this proportion had grown sevenfold to 40.7%. Also between 1998 and 2005 onward, there were considerably more 'no CPR' orders completed, which were obtained significantly earlier in the process, as well as more palliative care team involvement.

Unstable children in whom death is unexpected typically receive care in the PICU setting where various life-sustaining measures can be initiated while an effective treatment is sought. Our findings of an increasing proportion of deaths on the GPW suggest that deaths in the later time points were more likely to be 'expected'. As noted by others, this finding

may indicate that it has become more common for families of patients with life-limiting conditions to plan and discuss goals of care prior to death (6). Increased opportunity to engage in advanced care planning, as evidenced by the increase in consults to the palliative care team and earlier 'no CPR' orders, may result in families communicating their choice to have end-of-life care on the GPW or at home, rather than in the PICU. Choices about location of death in this cohort may have been influenced by the family's familiarity with the GPW milieu and the familiarity of the GPW staff with the child and family. Although data were not collected on outpatient deaths in this study, it is possible that more families were choosing end-of-life care at home over this time period. Growth in the proportion of children dying at home, coinciding with increases in the number of children living with chronic complex conditions and the availability of home palliative care, has been noted elsewhere (8).

In contrast with other research that suggests children with life-threatening conditions are living longer due to advances in medical and surgical care (1,2), the median age at death in our study decreased but did not vary significantly across the three time periods. The growth of palliative care across Canada has been associated with a substantial drop in the number of in-hospital deaths in patients of all ages through the facilitation of end-of-life care

at home (13). It is possible that older children in our study were more likely to be referred to palliative care services (12), and thus more likely to have the option of dying at home.

The limitations of our study include those inherent with the use of retrospective data collected cross-sectionally rather than longitudinally. Additionally, the small sample size, with data only collected on children who died within the hospital, may not provide a full perspective on trends in diagnoses, ages or shifting locations of care over the three time periods. Findings may not be generalizable to other settings, particularly those with limited palliative care services or with paediatric hospices. Our cohort of patients was defined by their location of optimal inpatient care—the GPW—rather than by a specific illness or category of disease. The subjective definition of a 'general paediatric condition' resulted in a heterogeneous group of research subjects included in the study, but on a pragmatic level permitted meaningful analyses of trends on the largest inpatient unit in our institution. While we realize that the term 'general paediatric condition' is artificial, we feel that it is a first step toward analyzing important trends in the patterns of death that occur in a tertiary care children's hospital beyond specific causes of mortality such as cancer, heart disease and deaths in the critical care units. In addition, while the definition is nonspecific, it remained consistent over the three time periods, allowing us to get a sense of changes over time in a similar group of patients.

The increased number of children dying on the GPW in our study demands consideration of the need for additional resources and education. Due to the relatively high rate of death in the PICU, critical care staff tend to feel confident caring for dying children (14,15) and have access to a wide array of evidence-based measures to support bereaved families (16,17) and each other (18,19). In contrast, general paediatricians report feeling unprepared to provide end-of-life care for their patients (20), and it is unclear how successfully supports used in the PICU can be transferred to the GPW setting.

CONCLUSION

The 15-year period from 1998 to 2012 has witnessed reductions in the number of inpatient general paediatric deaths at our tertiary care children's hospital. However, this overall decrease coincides with significant shifts in the characteristics of the experience of those who die in hospital: there is increased involvement of palliative care and decisions to not attempt CPR and ultimately a greater percentage of deaths on the GPW. These findings may have implications for the provision of quality inpatient end-of-life care for children in general paediatrics.

Table 1. Primary diagnosis by ICD-10 Chapter for the total sample

ICD-10 Chapter	n (%)
Diseases of the nervous system	27 (31.8)
Diseases of the respiratory system	12 (14.1)
Congenital malformations, deformations and chromosomal abnormalities	8 (9.4)
Diseases of the blood and immune system	6 (7.1)
Diseases of the circulatory system	6 (7.1)
Diseases of the digestive system	6 (7.1)
Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified	6 (7.1)
Endocrine, nutritional and metabolic diseases	5 (5.9)
Other*	9 (10.6)
Total	85 (100)

*We cannot report exact number of cases or proportion if less than five due to Research Ethics Board requirements. 'Other' includes the following ICD-10 Chapters: Conditions originating in the perinatal period, infectious and parasitic diseases, and injury, poisoning and other external causes.

Table 2. Location of death, 'no CPR' orders, palliative care team involvement and health care utilization by year

Variable	1998, n=35	2005, n=27	2012, n=23	P value*
Number (%) of deaths in PICU	33 (94.3)	16 (59.3)	16 (69.6)	<0.01
Number (%) with a 'no CPR' order at time of death	11 (31.4)	24 (88.9)	20 (87.0)	<0.01
Median (25th–75th percentile) number of days from 'no CPR' order to death	0 (0–1.0)	3.5 (1.0–10.5)	4.0 (1.0–13.5)	<0.01
Number (%) with a palliative care consultation prior to death	<5* (<10.0) [†]	19 (70.4)	17 (73.9)	<0.01
Median (25th–75th percentile) number of admissions to tertiary hospital over lifetime	1.0 (1.0–3.0)	3.0 (1.0–8.0)	1.5 (1.0–4.0)	0.04
Median (25th–75th percentile) number of admissions to tertiary hospital in last year of life	1.0 (1.0–3.0)	2.0 (1.0–4.0)	1.0 (1.0–2.0)	<0.01
Median (25th–75th percentile) proportion of days spent in tertiary hospital over lifetime	2.6 (0.5–18.9)	11.5 (2.3–21.4)	5.1 (0.3–34.0)	0.17
Median (25th–75th percentile) number of transfers to PICU over lifetime	1.0 (1.0–2.0)	1.0 (1.0–2.0)	1.0 (1.0–1.0)	0.12
Median (25th–75th percentile) number of transfers to PICU in last year of life	1.0 (1.0–1.0)	1.0 (0–1.0)	1.0 (1.0–1.0)	0.06
Median (25th–75th percentile) length of stay in hospital during final admission (days)	6.0 (2.0–30.0)	12.0 (3.0–23.0)	12.0 (2.0–28.0)	0.64

CPR Cardiopulmonary resuscitation; PICU Paediatric intensive care unit.

*P value is derived from a chi-square test for categorical variables and from a Kruskal–Wallis test for continuous variables; [†]We cannot report exact number of cases or proportion if less than five due to Research Ethics Board requirements.

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