

Study finds one in five children who might benefit from pediatric palliative care do not

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The University of Toronto's Faculty of Nursing today announced that only 18 per cent of children with life-threatening conditions access specialized pediatric palliative care in Canada, a 13 per cent increase since 2002. 25 per cent of those who receive this type of care only do so for less than eight days prior to death. The new study led by Dr. Kimberley Widger, assistant professor at the Lawrence S. Bloomberg Faculty of Nursing, is now published online by *CMAJ Open* (*Canadian Medical Association Journal*).

"We completed a similar study 10 years ago and wanted to see how the landscape of pediatric palliative care provision changed over time," says Widger. "With the advent of Medical Assistance in Dying, and the possibility of extending this option to children, we felt it was important to update our information about the proportion of children receiving specialized care."

Pediatric palliative care is an active and total approach to care for children with life-threatening conditions and their families aimed at managing symptoms and optimizing quality of life throughout the disease process. While every health professional should be able to incorporate aspects of palliative care into usual care provision, the study finds that there is growing evidence to suggest that specialized services may provide improved quality of care. Researchers examined the programs available in Canada and the children who received this specialized care, as well as estimating the proportion of children who might benefit and actually receive specialized care.

Key Highlights:

- The number of programs grew from eight to thirteen between 2002 and 2012 and included three free-standing pediatric hospices;
- The number of children who received specialized care during each one year study period increased 4-fold from 371 to 1401;
- Of the children who received care during 2012, just over one third were under one year old;
- Only 15 per cent of the children had cancer, while 36 per cent had a congenital illness or condition that arises just before or after birth;
- Children who received care through one of the programs that included a free-standing hospice tended to be older and received specialized services for longer than those who received care from a program without a hospice;
- Of the children who died in 2012, half received specialized care for only the last 30 days of life and one quarter only received specialized care for one week or less;
- In 2002, we estimated that 5 per cent of children who might benefit received specialized pediatric palliative care; as of 2012 this proportion rose to 18 per cent;
- Despite a 4-fold increase in the number of children who received care between 2002 and 2012, staffing levels over this period only increased less than 3-fold, thus staffing resources are not keeping up with demand.

The Study

Specialized pediatric palliative care programs were included in the study based on provision of care by health professionals with expertise in both pediatrics and palliative care with designated resources to deliver [specialized care](#) to children with any type of life-threatening condition.

An investigator from each program provided information about the services provided during 2012 and all children who received care through the program during that calendar year. Two methods were used to estimate the proportion of children who received care based on data available through Statistics Canada on the population of children less than 19 years of age and the total number and causes of death for children during 2012. Both methods resulted in the same proportion estimates.

While there has been program growth and improved reach of services over time, barriers remain that prevent the vast majority of [children](#) with life-threatening conditions from receiving specialized pediatric [palliative care services](#).

The full study titled "Pediatric palliative care in Canada in 2012: A cross-sectional descriptive study" is available online at [CMAJ Open](#).

More information: K. Widger et al, Pediatric palliative care in Canada in 2012: a cross-sectional descriptive study, *CMAJ Open* (2016). [DOI: 10.9778/cmajo.20160054](https://doi.org/10.9778/cmajo.20160054)

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