



## Need for Pediatric Data: CNPCC response on CIHI Report on Access to Palliative Care in Canada

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The Canadian Network of Palliative Care for Children (CNPPC) is a network of Canadians who provide or are interested in Palliative Care for children and is a Special Interest Group of the Canadian Hospice Palliative Care Association. CNPCC is committed to the development of national standards, outcome measures and quality indicators to shape palliative care policy for children in Canada and welcomes the ongoing work of the Canadian Institute for Health Information (CIHI) in furthering this goal.

In 1963, Patrick Bouvier Kennedy was born three weeks early and tragically died two days later from respiratory distress syndrome. Today, although often needing weeks of support including support for breathing and support for initiating feeds by mouth, babies born between 34- and 36-weeks gestational age have a nearly 100% chance of survival<sup>1</sup>. In addition to supports which allow infants born prematurely to survive, technology has advanced so that tube feeding allow children who are unable to take food by mouth to survive, tracheostomy tubes can be placed to allow an infant to grow until they are big enough for surgical repair of structural abnormalities of their airway, and long-term breathing support is available for children unable to support effective breathing on their own. Surgical procedures can improve survival in children born with structural abnormalities of their heart, or who are born with abnormalities of their bowel. Children born with conditions which in the past were called “lethal” are being supported to survive into early adulthood, with the children and youth themselves and their families describing good quality of life.

Many of these infants, children, and youth benefit from a palliative approach to care. This does not mean that care is not provided, but that care and interventions are carefully chosen to improve the quality of the child’s life. The Government of Canada’s 2018 *Framework on Palliative Care in Canada* stated a goal of improving equitable access to palliative care. The recent Canadian Institute for Health Information (CIHI) report on Access to Palliative Care in Canada<sup>2</sup> is a welcome summary of the data which is collected in Canada. The Canadian Network of Palliative Care for Children applauds the work that has been done but would like to draw attention to the fact that the data for this report is collected on Canadians aged 18 and older, thus there is no information about the current state of palliative care for children in Canada. This lack of data may contribute to the perception that a need for palliative care does not exist for infants, children, and youth.

In 2002, Widger et al<sup>3</sup> provided information about Pediatric Palliative Care programs in Canada based on data collected from surveys and review of medical records at each site providing care. They found that care was provided for a diverse population of patients with a wide range of age and disease conditions. Only a small percentage of children who die, however, received services from these dedicated programs. In 2012, Widger et al<sup>4</sup> repeated this study, again using surveys and data collected from medical records at each site. This second study found that program growth and changes in patients’ demographic and clinical characteristics indicate improved reach of programs. Barriers remain that

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prevent most children with life-threatening conditions from receiving specialized pediatric palliative care services.

The CIHI report provides both the objective data and the caregiver perspective on the spotlight issues, including whether death occurs at home or in the community, the role of hospice care in palliative and end-of-life care, who is receiving palliative care, and who isn't receiving palliative care. It reviews care received at home, in long term care facilities, in hospital, and in emergency departments. All these perspectives are relevant to infants, children and youth and their families who are or are not receiving palliative care.

For infants, children and youth and their families, for the people who care for them and for those who are moving to the adult care environment, moving forward needs to include a capacity to collect data about Canadians under the age of 18, collecting data specific to all the categories outlined in the CIHI report. Researchers such as Dr. Widger and her colleagues are well positioned to advise the development of provincial and national datasets to capture this information.

1. Escobar GJ, Clark RH, Greene JD. Short-term outcomes of infants born at 35- and 36-weeks gestation: we need to ask more questions. *Semin Perinatol.* 2006 Feb;30(1):28-33. doi: 10.1053/j.semperi.2006.01.005. PMID: 16549211.
2. Canadian Institute for Health Information. *Access to Palliative Care in Canada, 2023.* Ottawa, ON: CIHI; 2023
3. Widger K, Davies D, Drouin DJ, Beaune L, Daoust L, Farran RP, Humbert N, Nalewajek F, Rattray M, Rugg M, Bishop M. Pediatric patients receiving palliative care in Canada: results of a multicenter review. *Arch Pediatr Adolesc Med.* 2007 Jun;161(6):597-602. doi: 10.1001/archpedi.161.6.597. PMID: 17548766.
4. Widger K, Davies D, Rapoport A, Vadeboncoeur C, Liben S, Sarpal A, Stenekes S, Cyr C, Daoust L, Grégoire MC, Robertson M, Hodgson-Viden H, Laflamme J, Siden H. Pediatric palliative care in Canada in 2012: a cross-sectional descriptive study. *CMAJ Open.* 2016 Oct 11;4(4):E562-E568. doi: 10.9778/cmajo.20160054. PMID: 28018868; PMCID: PMC5173480.

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