



# The State of Pediatric Palliative Care in Canada

Rebecca Vachon  
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A Cardus Research Report

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## About the Author



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## Key Points

- Pediatric palliative care (PPC) is an approach to caring for children facing life-limiting or life-threatening illnesses or conditions, and their families, in a holistic way. This includes managing physical symptoms; supporting psychosocial, spiritual, and emotional needs; and assisting in grief and bereavement.
- In Canada, the state of pediatric palliative care requires attention—particularly amid Canada’s consideration of expanding euthanasia and assisted suicide as “medical assistance in dying,” or MAID, to children. A review of available research reveals that some improvements in the provision of PPC have occurred, including an increase in the number of specialist PPC teams and the number of pediatric hospices operating in Canada. Yet, large gaps remain and require attention and redress.
- There are high numbers of children who would benefit from PPC but are not receiving it, or are receiving it only within the last weeks or days of life. Instead, PPC should be integrated early, upon diagnosis of a serious illness or condition. Problems with access and quality of PPC are more pronounced in certain areas, including low-income and rural areas, as well as among Indigenous populations, where significant disparities between Indigenous and non-Indigenous children exist in health outcomes and in healthcare.
- In terms of quality of care, most children are not receiving home-based PPC and are unable to die at home. The vast majority of children die in hospitals instead, and often in acute-care settings, such as emergency departments and pediatric intensive-care units. This may result in the receipt of high-intensity interventions in these settings at the end of life, which may not adequately support a focus on comfort care or quality of life.
- This paper highlights the urgent need for action in order to address these inequities and gaps, particularly heightened by the contemplation of expanding euthanasia and assisted suicide as MAID to children.

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## Introduction

Illness and loss at any age are extremely difficult trials for patients and their families, but especially so when the patient is a child. In Canada, approximately 2,400 children aged nineteen and under die each year as a result of an illness.<sup>1</sup>

Pediatric (sometimes spelled “paediatric”) palliative care (PPC) is an approach to caring for children facing life-limiting or life-threatening illnesses or conditions, and their families, in a holistic way that includes managing physical symptoms; supporting psychosocial, spiritual, and emotional needs; and assisting in grief and bereavement. As affirmed in internationally established standards of care, all children with such illnesses should be able to access and receive PPC.<sup>2</sup>

Currently, Canada does not maintain national standards for palliative care, and the definition, provision, and context of pediatric palliative care faces a lack of consensus. This report assesses how well Canada is providing palliative care for pediatric populations by reviewing the academic literature, with a focus on Canadian studies from the past ten years, as well as reports and documents from relevant governmental, non-governmental, and healthcare bodies.

This topic is particularly important because children in Canada may become legally eligible for euthanasia and assisted suicide, referred to in Canadian legislation as “medical assistance in dying,” or MAID. In February 2023, the federal parliament’s Special Joint Committee on Medical Assistance in Dying (AMAD) completed its statutory review of the laws governing euthanasia and assisted suicide. It recommended, among other expansions, amendments to eligibility to allow euthanasia and assisted suicide for “minors deemed to have the requisite decision-making capacity upon assessment,” with the caveat that it be restricted to such children “whose natural death is reasonably foreseeable.”<sup>3</sup>

This proposed expansion raises important questions about the capacity of children to make these life-and-death decisions, the role and rights of parents in such cases, and the context in which such decisions are made. These questions all warrant further consideration, but this report focuses on the important context of existing palliative care available to children who have been diagnosed with a serious illness or condition, regardless of whether their death is reasonably foreseeable.

<sup>1</sup> Statistics Canada, “Table 13-10-0392-01. Deaths and Age-Specific Mortality Rates, by Selected Grouped Causes,” <https://doi.org/10.25318/1310039201-eng>.

<sup>2</sup> F. Benini et al., “International Standards for Pediatric Palliative Care: From IMPaCCT to GO-PPaCS,” *Journal of Pain and Symptom Management* 63, no. 5 (2022): e532, <https://doi.org/10.1016/j.jpainsymman.2021.12.031>. The IMPaCCT (International Meeting for Palliative Care in Children, Trento) standards established for Europe in 2007 were subsequently revised and expanded to the broader international context through the GO-PPaCS (Global Overview – Pediatric Palliative Care Standards) project in 2022.

<sup>3</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Medical Assistance in Dying in Canada: Choices for Canada*, 44th Parl, 1st Sess (February 2023) at 8, <https://www.parl.ca/DocumentViewer/en/44-1/AMAD/report-2>.

This report begins by defining PPC, reviewing the specific challenges for pediatric populations, and examining the benefits that it offers to children and their families and to the healthcare system more broadly. Next, this report examines its current availability, including inequities of access, and its current quality, including how early or late PPC is introduced within the trajectory of a child's illness or condition as well as the location of death and the use of high-intensity interventions and acute care. Finally, recommendations derived from the literature are presented for the improvement of PPC services and for further research, to better support these children and their families and to maximize the quality of end-of-life care they experience.

## What is Pediatric Palliative Care?

### Pediatric Palliative Care is Holistic

As with adult palliative care, the defining characteristic of pediatric palliative care is its aim to address the whole person, including the physical, psychosocial or emotional, and spiritual needs of children and their families, helping to manage symptoms and provide quality of life.<sup>4</sup> The World Health Organization defines PPC as “the active total care of the child's body, mind and spirit, and also involves giving support to the family.”<sup>5</sup>

Both adult and pediatric palliative care teams ideally include professionals from a variety of medical and other fields who can provide this multi-faceted support, including doctors, nurses, and other medical specialists, as well as counsellors, therapists, social workers, and chaplains. This holistic and multidisciplinary approach to care is “both a philosophy and a delivery model of specialized care focusing on total comprehensive care for infants, children, and adolescents and their families across the illness trajectory and into bereavement.”<sup>6</sup> It enables children and their families to “live their fullest” amid a life-threatening or life-limiting illness or condition.<sup>7</sup> This approach is increasingly recognized by practitioners for its ability to support children and their families as they navigate illness, death, and bereavement.

<sup>4</sup> R. Drake and E. Chang, “Palliative Care of Pediatric Populations,” in *Textbook of Palliative Care*, ed. R.D. MacLeod and L. van den Block (Cham: Springer, 2018), 2, [https://doi.org/10.1007/978-3-319-31738-0\\_67-1](https://doi.org/10.1007/978-3-319-31738-0_67-1).

<sup>5</sup> World Health Organization, “Palliative Care for Children,” June 1, 2023, <https://www.who.int/europe/news-room/factsheets/item/palliative-care-for-children>.

<sup>6</sup> J.M.G. Bally, N.R. Smith, and M. Burles, “Pediatric Palliative and Hospice Care in Canada,” in *Hospice Palliative Home Care and Bereavement Support*, ed. L. Holtlander, S. Peacock, and J. Bally (Cham: Springer, 2019), 256–57, [https://doi.org/10.1007/978-3-030-19535-9\\_19](https://doi.org/10.1007/978-3-030-19535-9_19).

<sup>7</sup> S.-M. Wang, P.B. Yost, and L. Sender, “Pediatric Palliative Care,” in *Essentials of Palliative Care*, ed. N. Vadivelu, A.D. Kaye, and J.M. Berger (New York: Springer, 2013), 444, [https://doi.org/10.1007/978-1-4614-5164-8\\_25](https://doi.org/10.1007/978-1-4614-5164-8_25).

## Pediatric Palliative Care Begins at Diagnosis

Despite the popular conception that palliative care is used only at the very end of life, PPC (like palliative care for adults) is best integrated *early*, upon *diagnosis* of a life-limiting or life-threatening disease or condition. “Life-limiting” conditions are diseases or illnesses affecting the quality of life but not necessarily its longevity—though often they may be terminal, or incurable. “Life-threatening” conditions are diseases or illnesses presenting significant risk to life, often requiring hospitalization and treatment.<sup>8</sup> These terms are used to indicate that the reach of pediatric palliative care goes beyond the immediate, imminent end of life, to support children and families at diagnosis—which, in the case of congenital disease, for example, can be from birth on—throughout the trajectory of their condition, regardless of whether it ends in bereavement.

Incorporating palliative care early can support the management of symptoms from the onset, which can prevent these symptoms from becoming overwhelmingly distressing and difficult throughout disease progression and especially at the end of life.<sup>9</sup> Importantly, early integration does not mean that curative or life-extending treatments have ceased. PPC should be used *concurrently* or *in parallel* with these treatments. Integrating PPC with other treatments offers significant benefits. It can “alleviate symptoms[,] improve quality of life and patient satisfaction, reduce caregiver burden, potentially lead to more appropriate referral and utilization of

hospice services, reduce inappropriate use of intensive care, and possibly increase survival duration.”<sup>10</sup>

*PPC is best integrated early, upon diagnosis of a life-limiting or life-threatening disease or condition.*

Thus, early integration can support better comfort care and quality of life even in the midst of ongoing treatment of the disease or ongoing life-extending therapies, and, if treatments or therapies are unsuccessful or no longer desired, PPC can help patients and their families transition to a primary focus on quality of life as the end of life approaches.

Early integration of PPC can also help patients and their families plan for care, avoid or assist with unplanned visits to the emergency department or intensive-care unit, lessen high-intensity interventions when these are uncondusive to care goals, and allow patients to die at home if this is the location they prefer.

<sup>8</sup> R.C. Macauley, “The Limits of ‘Life-Limiting,’” *Journal of Pain and Symptom Management*, 57, no. 6 (June 2019): 1176–81, <https://doi.org/10.1016/j.jpainsymman.2019.03.010>. Although some debate remains over these particular terms, they are currently the most widely used and thus are adopted here.

<sup>9</sup> C. Sepúlveda et al., “Palliative Care: The World Health Organization’s Global Perspective,” *Journal of Pain and Symptom Management* 24, no. 2 (August 2002): 92, [https://doi.org/10.1016/s0885-3924\(02\)00440-2](https://doi.org/10.1016/s0885-3924(02)00440-2); D. Levine et al., “Best Practices for Pediatric Palliative Cancer Care: A Primer for Clinical Providers,” *Journal of Supportive Oncology* 11, no. 3 (September 2013), <https://doi.org/10.12788/j.suonc.0012>; Drake and Chang, “Palliative Care of Pediatric Populations”; Benini et al., “International Standards for Pediatric Palliative Care”; Bally, Smith, and Burles, “Pediatric Palliative and Hospice Care in Canada.”

<sup>10</sup> Levine et al., “Best Practices for Pediatric Palliative Cancer Care,” 123.



## Pediatric Palliative Care Can Be Delivered in Various Settings

PPC may be delivered in various settings, including in hospital, at home, and in hospice, and the setting may shift over time.<sup>11</sup> Delivery may vary based on availability of care in particular regions, specificities and complexities of patients' conditions, and the desires of the family.<sup>12</sup> For instance, while some families may wish to have the child receive PPC within the home, others may prefer a hospice environment, depending on the needs associated with the illness or condition and each family's individual circumstances. Some research has pointed to a general preference among families for care that allows the child to die at home.<sup>13</sup> Despite this preference, PPC in Canada is usually delivered in hospital rather than at home, although the number of free-standing hospices has also increased in recent years.<sup>14</sup>

## Pediatric Palliative Care Encompasses the Family

Although palliative care for adults also considers the family unit, the attention to family is heightened in the pediatric context. Not only is a child particularly dependent on parents, but the diagnosis, illness, and associated death of a child can be especially distressing for the family and broader community. The death of a child can result in long-term and complicated grief and mental-health challenges, and a child's diagnosis can mean that "a family's faith, hope, and belief and trust in the future can be extensively compromised and even shattered."<sup>15</sup> As a result, the care must address the needs of caregivers, siblings, and the whole family, both during illness and bereavement.<sup>16</sup>

## Pediatric Palliative Care Requires Unique Considerations for Pediatric Populations

The pediatric population presents unique challenges for palliative care. These challenges can be grouped into two main categories: (1) the rarity and diversity

<sup>11</sup> While the terms "palliative care" and "hospice care" are usually used interchangeably, American research often refers to hospice care as where death is imminent and treatment has ceased, as opposed to palliative care, which can begin with diagnosis and exist parallel to treatment. For example, see Bally, Smith, and Burles, "Pediatric Palliative and Hospice Care in Canada." In this report, "pediatric palliative care" is used to refer to palliative care generally, regardless of what context it is being delivered in (hospice, hospital, or at home).

<sup>12</sup> E.E. Johnston et al., "Hospital or Home? Where Should Children Die and How Do We Make That a Reality?," *Journal of Pain and Symptom Management* 60, no. 1 (July 2020): 106–15, <https://doi.org/10.1016/j.jpainsymman.2019.12.370>.

<sup>13</sup> M. Bluebond-Langner et al., "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," *Palliative Medicine* 27, no. 8 (September 2013): 705–13, <https://doi.org/10.1177/0269216313483186>.

<sup>14</sup> Bally, Smith, and Burles, "Pediatric Palliative and Hospice Care in Canada."

<sup>15</sup> Bally, Smith, and Burles, "Pediatric Palliative and Hospice Care in Canada," 255; S.N.H. Buang et al., "Palliative and Critical Care: Their Convergence in the Pediatric Intensive Care Unit," *Frontiers in Pediatrics* 10, no. 907268 (June 2022): 1–7, <https://doi.org/10.3389/fped.2022.907268>.

<sup>16</sup> Bally, Smith, and Burles, "Pediatric Palliative and Hospice Care in Canada"; Drake and Chang, "Palliative Care of Pediatric Populations," 10.

of children’s medical conditions and illnesses, and their variable prognosis and trajectories; and (2) the child’s development, the state of which can evolve within individual patients but also varies significantly between children of different ages and with different conditions.

Children facing life-limiting and life-threatening conditions or illnesses are in a minority, both because these situations are rare among children and because the population of pediatric patients relative to adult patients is much smaller.<sup>17</sup> Many pediatric conditions are congenital or genetic, and are often only found in children.<sup>18</sup> In adults, by contrast, cancer is the leading condition in which palliative care is used.<sup>19</sup>

These rare conditions among children can vary significantly. They include incurable, progressive conditions that may require extended periods of palliative care, such as Batten disease; conditions in which premature death will occur but in which care can prolong and improve the quality of life, such as cystic fibrosis; and non-progressive conditions that present complex needs or complications and the possibility of premature death, such as severe cerebral palsy. In other cases, such as cancer, curative treatments may be used but could fail.<sup>20</sup> A final category includes children *in utero* and infants, who may not survive birth or may survive only for a short time thereafter.<sup>21</sup>

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Because the rarity and complexity of pediatric illnesses create challenges for research, with relatively rare diagnoses resulting in smaller cohorts to study,<sup>22</sup> it is more difficult to map out the trajectory of a disease or condition, and to plan for and provide PPC. Overall, the pediatric population frequently presents highly complex conditions and

<sup>17</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 2.

<sup>18</sup> Congenital describes “a condition that is recognized at birth or that is believed to have been present since birth,” irrespective of cause, whether genetic and inherited or due to an environmental cause. J. Law and E. Martin, eds., “Congenital,” in *Concise Medical Dictionary* (New York: Oxford University Press, 2020).

<sup>19</sup> C. Feudtner et al., “Pediatric Palliative Care Patients: A Prospective Multicenter Cohort Study,” *Pediatrics* 127, no. 6 (June 2011): 1094–101, <https://doi.org/10.1542/peds.2010-3225>; Canadian Institute for Health Information, “Access to Palliative Care in Canada, 2023,” April 27, 2023, <https://www.cihi.ca/en/access-to-palliative-care-in-canada>.

<sup>20</sup> Further details of the categorization can be found in *A Guide to Children’s Palliative Care*, originally published in 1997 and now in its fourth edition. L. Chambers, *A Guide to Children’s Palliative Care*, 4th ed. (Bristol: Together for Short Lives, 2018), <https://www.togetherforshortlives.org.uk/app/uploads/2018/03/TfSL-A-Guide-to-Children%E2%80%99s-Palliative-Care-Fourth-Edition-FINAL-SINGLE-PAGES.pdf>.

<sup>21</sup> Benini et al., “International Standards for Pediatric Palliative Care,” 533.

<sup>22</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 14.

is more likely to receive ongoing curative and/or life-prolonging treatments alongside receiving palliative care.<sup>23</sup> Pediatric populations thus often require specialist palliative care<sup>24</sup> (discussed in the next section), which can also continue over longer periods of time, from months to years.

Developmental differences within children—both across the age range and due to particular conditions—also pose challenges. As the World Health Organization puts it, “children are not little adults,” and their care needs to consider these differences.<sup>25</sup> This can be rendered more challenging when some aspects of medical care are designed for adult bodies. For instance, administering medications can be more difficult due to the need to adjust dosages for children’s bodies. Providing the needed dosage in a highly precise way is more difficult when liquid or easy-to-dose medications are not available and medications produced for adult bodies must be cut up instead.<sup>26</sup>

Additionally, with pediatric patients ranging in age from children *in utero* to teenagers, and with certain conditions that can involve cognitive and neurological impairments or disabilities, the wide array of developmental states poses challenges. Under these conditions, children’s development may not simply increase in a linear fashion as they age, requiring ongoing assessment by clinicians.<sup>27</sup> Likewise, the way in which the child’s overall physical and cognitive development may change over time must be factored into care and ongoing assessment, particularly in cases where the child may be receiving PPC over an extended period.

Impairments, disabilities, and varied states of development have considerable impact on “the degree of dependence on caregivers, their role within the family and community, and . . . [their] awareness and understanding of illness and death.”<sup>28</sup> They also have an impact on how children interact with their medical care team, as children may also be unable or have limited capacity to understand and communicate their symptoms. Pain, for example, tends to be underreported by children.<sup>29</sup>

## The Benefits of Pediatric Palliative Care

Given the complexities that are often involved in children’s conditions, however, it is only with specialist PPC (versus generalist PPC) that the benefits of palliative care

<sup>23</sup> Levine et al., “Best Practices for Pediatric Palliative Cancer Care,” 115.

<sup>24</sup> “Specialist” palliative care and “specialized” palliative care are both terms used in the literature. This report uses “specialist” but some direct quotations of academic literature in this paper use the other term.

<sup>25</sup> World Health Organization, *Integrating Palliative Care and Symptom Relief into Paediatrics: A WHO Guide for Health-Care Planners, Implementers and Managers* (Geneva: World Health Organization, 2018), 7, <https://apps.who.int/iris/handle/10665/274561>.

<sup>26</sup> World Health Organization, *Integrating Palliative Care*, 8.

<sup>27</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 9.

<sup>28</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 2.

<sup>29</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 10.

for children have been clearly documented in research, both in other jurisdictions<sup>30</sup> and in Canada.<sup>31</sup> Involvement of specialist PPC teams—whether through direct care or through specialist teams’ support of local clinicians providing direct care—is associated with fewer emergency visits, shorter hospital stays, less intensive or aggressive interventions, and a lower likelihood of dying in hospital in cases where the illness ends in death.<sup>32</sup> As Bally, Smith, and Burles note, specialist PPC “can greatly improve the quality of life of both the child and their entire family, ease overall suffering, enhance functioning, and support family growth in all dimensions of well-being.”<sup>33</sup>

In simpler terms, the involvement of specialist PPC teams can enable patients to receive the symptom relief that they need when those symptoms might otherwise result in the child being taken to the emergency department or admitted to the intensive-care unit. And while emergencies may still necessitate unplanned hospital visits or admissions, alleviating this need as much as possible by ensuring the management of distressing symptoms and providing high-quality communication with families and caregivers can be extremely beneficial to all involved. Likewise, being able to receive care and die at home when the care is provided at the end of life can support quality of life and comfort for the child and support the bereavement of families.<sup>34</sup>

Specialist PPC can reduce the use of acute or high-intensity interventions, particularly in the last stages of life. Such interventions can include the use of intubation, feeding tubes, CPR, mechanical ventilation, or admission to the intensive-care unit. While these high-intensity interventions can be appropriate and necessary, and in some cases be in place for long periods of time, in circumstances such as the final stages of life when the priority may be on comfort care, the benefits of such measures may not outweigh the discomfort or adverse impact on quality of life.

Although cost saving should not be the driving determinant for children’s healthcare, from a healthcare-system perspective it is notable that PPC is associated with cost savings, alongside the benefits provided for children and their families. It is associated with less use of hospitals and overall lower healthcare costs in patients’ last year of life.<sup>35</sup> Because costs are often higher when receiving acute care, such as care within

<sup>30</sup> J. Taylor et al., “Specialist Paediatric Palliative Care for Children and Young People with Cancer: A Mixed-Methods Systematic Review,” *Palliative Medicine* 34, no. 6 (2020): 731–75, <https://doi.org/10.1177/0269216320908490>.

<sup>31</sup> K. Widger et al., “Predictors of Specialized Pediatric Palliative Care Involvement and Impact on Patterns of End-of-Life Care in Children with Cancer,” *Journal of Clinical Oncology* 36, no. 8 (March 10, 2018): 801–7, <https://doi.org/10.1200/JCO.2017.75.6312>.

<sup>32</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence*, 44th Parl, 1st Sess, No 24 (1 November 2022) at 13, <https://parl.ca/DocumentViewer/en/44-1/AMAD/meeting-24/evidence>; Widger et al., “Predictors of Specialized Pediatric Palliative Care Involvement.”

<sup>33</sup> Bally, Smith, and Burles, “Pediatric Palliative and Hospice Care in Canada,” 254.

<sup>34</sup> Johnston et al., “Hospital or Home?”

<sup>35</sup> D. Lysecki et al., “Children’s Health Care Utilization and Cost in the Last Year of Life: A Cohort Comparison with and without Regional Specialist Pediatric Palliative Care,” *Journal of Palliative Medicine* 25, no. 7 (July 2022): 1038, <https://doi.org/10.1089/jpm.2021.0175>.

the emergency room or intensive-care unit, the association of PPC with requiring less acute care also involves a cost saving for the healthcare system.<sup>36</sup>

## Provision of Pediatric Palliative Care

Having established both the challenges and benefits of PPC, this section now examines the provision of PPC. However, assessing adult (age nineteen and up) palliative care in Canada is already a challenge, as the Canadian Institute for Health Information (CIHI) has acknowledged in 2018 and 2023 reports.<sup>37</sup> These reports note limitations in assessment due to regional differences in reporting, among other issues. The Canadian Society of Palliative Care Physicians further emphasized the significance of these limitations in a response to the 2023 report, stating that “the limitations of the data set used . . . make it difficult when trying to generalize across jurisdictions.” Additionally, the Society stated, the admission by CIHI of a “lack of ‘consensus on what receiving palliative care means and what services this should include’ leaves further questions about the strength of conclusions drawn.”<sup>38</sup>

Based on the available data, CIHI’s review of adult palliative care reveals ongoing issues both in access to services and in research and reporting on the availability and quality of palliative care services. The Canadian Society of Palliative Care Physicians’ response to CIHI expresses even stronger concern, noting that, “as physicians delivering palliative care, we continue to experience widening gaps in access and quality which have only been aggravated by post-pandemic strains.”<sup>39</sup>

Reporting issues are exacerbated by Canada’s lack of “minimum standards in place to support the provision of high-quality palliative care.”<sup>40</sup> The absence of national standards persists in spite of the *Framework on Palliative Care in Canada Act* passed by Parliament in 2017 and the subsequent framework and action plan developed by Health Canada.<sup>41</sup>

<sup>36</sup> K. Widger et al., “Children’s End-of-Life Health Care Use and Cost,” *Pediatrics* 139, no. 4 (2017): e20162956, <https://doi.org/10.1542/peds.2016-2956>.

<sup>37</sup> The Canadian Institute for Health Information reports on access to palliative care for 2018 and 2023 can be accessed at <https://www.cihi.ca/en/access-to-palliative-care-in-canada>. Both reports only examine palliative care for adults.

<sup>38</sup> Canadian Society of Palliative Care Physicians, “Need for Better Data: CSPCP Response on CIHI Report on Access to Palliative Care in Canada,” May 2023, 1, <https://www.cspcp.ca/wp-content/uploads/2023/06/CSPCP-Statement-response-to-CIHI-Report-on-Access-to-Palliative-Care-in-Canada-May-2023.pdf>.

<sup>39</sup> Canadian Society of Palliative Care Physicians, “Need for Better Data,” 1.

<sup>40</sup> Canadian Society of Palliative Care Physicians Human Resource Committee, “Highlights from the National Palliative Medicine Survey,” May 2015, 21, <https://cspcp.ca/wp-content/uploads/2023/02/PM-Survey-Final-Report-EN.pdf>; B. Pesut et al., “Is Progress Being Made on Canada’s Palliative Care Framework and Action Plan? A Survey of Stakeholder Perspectives,” *BMC Palliative Care* 21, no. 182 (2022): 2, <https://doi.org/10.1186/s12904-022-01074-4>.

<sup>41</sup> Health Canada, “Framework on Palliative Care in Canada,” Government of Canada, December 4, 2018, <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html>; Health Canada, “Action Plan on Palliative Care,” August 20, 2019, <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/action-plan-palliative-care.html>.

Because CIHI's reports examine palliative care for adults only, the Canadian Network of Palliative Care for Children responded by highlighting CIHI's lack of reporting on pediatric palliative care, which means the extent of the true need for these services remains unknown. The Network stresses that, for the sake of Canadian infants, children, youth and their families, future work by CIHI "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."<sup>42</sup> (By contrast, "Atlas" projects in Scotland and Europe include PPC in their data collection.<sup>43</sup>)

## Availability

Given that CIHI's reporting excludes children, assessing the current availability of PPC is challenging. The most comprehensive academic study is by K. Widger et al., whose work is referenced in this report repeatedly due to Widger's role in studying PPC in Canada. This study evaluates PPC provision from 2002 to 2012 and found a modest increase in the number of programs, from eight in 2002 to thirteen in 2012, with ten of these being hospital-based and three in free-standing hospices.<sup>44</sup> In testimony before the Parliament's AMAD in 2022, Widger, the lead author of this study, stated that the number of specialist PPC teams had increased to seventeen in 2022.<sup>45</sup>

As of November 2023, the Canadian Network of Palliative Care for Children identified PPC programs within thirteen urban hospitals and eight urban pediatric hospices.<sup>46</sup> No PPC programs are listed as available in any of the territories, however, and only one, in Halifax, is available in all of Atlantic Canada. The pediatric hospices are found only in British Columbia (2), Alberta (1), Ontario (3), and Quebec (2), with none in Saskatchewan, Manitoba, the territories, or Atlantic Canada.

On a positive front, Widger et al.'s study points to a four-fold increase in the number of children who received specialist PPC in Canada from 2002 to 2012. Yet it also

<sup>42</sup> Vadeboncoeur, C., "Need for Pediatric Data: CNPCC Response on CIHI Report on Access to Palliative Care in Canada," Canadian Hospice Palliative Care Association, June 2023, [https://www.chpca.ca/wp-content/uploads/2023/06/UPDATED\\_CNPCC-Response-to-CIHI-Report-on-Access-to-Palliative-Care-in-Canada-6-June-2023.pdf](https://www.chpca.ca/wp-content/uploads/2023/06/UPDATED_CNPCC-Response-to-CIHI-Report-on-Access-to-Palliative-Care-in-Canada-6-June-2023.pdf).

<sup>43</sup> These projects are geographical representations of the availability and extent of palliative care services in various countries around the world, a methodology established by The Atlantes program based at the University of Navarra in Spain. An Atlas research project is currently underway in Canada, under the leadership of non-profit Pallium Canada. See H. Inbadas, M. Gillies, and D. Clark, "Scottish Atlas of Palliative Care," Glasgow End of Life Studies Group, University of Glasgow, 2016, [https://www.gla.ac.uk/media/Media\\_486122\\_smx.pdf](https://www.gla.ac.uk/media/Media_486122_smx.pdf); N. Arias-Casais et al., *EAPC Atlas of Palliative Care in Europe 2019* (Vilvoorde: EAPC Press, 2019), <https://hdl.handle.net/10171/56787>; Pallium Canada, "Research and Impact," <https://www.pallium.ca/research-impact/>. Additional information on Pallium Canada's Atlas research project is also available in a short video: J. Pereira, "The Canadian Palliative Care Atlas," Pallium Canada, September 20, 2019, YouTube video, <https://www.youtube.com/watch?v=Om0Trf-X9EA>.

<sup>44</sup> K. Widger et al., "Pediatric Palliative Care in Canada in 2012: A Cross-Sectional Descriptive Study," *CMAJ Open* 4, no. 4 (2016): e562–68, <https://doi.org/10.9778/cmajo.20160054>.

<sup>45</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence* at 13.

<sup>46</sup> Canadian Hospice Palliative Care Association, "Canadian Network of Palliative Care for Children," accessed October 16, 2023, <https://www.chpca.ca/projects/canadian-network-of-palliative-care-for-children/>.

notes that 81 percent of children who might have benefited from receiving this PPC did not receive it, and 51 percent of children who died in 2012 and received specialist PPC only received it in the last thirty days prior to the end of life.<sup>47</sup> In recent testimony to AMAD, Widger indicated that statistics had not yet been obtained to provide an indication of how many children were actually receiving care as of 2022, but noted that “based on a couple of relatively recent studies we’ve done just focused on Ontario, about one in three children who died from a life-threatening condition received care from one of these teams.”<sup>48</sup>

This more recent Ontario data may suggest a positive improvement, but it is unclear if these results hold true for the country as a whole. Even if it does, a significant gap still exists between children who would benefit from receiving PPC and those who actually are. Overall, therefore, there are positive signs of improvement, but it has occurred slowly, and gaps and inequities in access remain.

### **Inequities in Access in Rural and Indigenous Communities**

The concentration of specialist PPC in urban centres raises questions about equity of access for rural Canadians, particularly those in remote settings.<sup>49</sup> Research has pointed to geographic and socioeconomic disparities, such as a 2018 study of Ontario children with cancer, finding that “those with lower incomes or living in rural areas were less likely to receive SPPC [specialist PPC].”<sup>50</sup>

Although PPC teams can consult with local providers, the complexity of children’s care often requires in-person access. Those who live in rural or remote communities may have to travel, which creates a separation from the community and can result in additional challenges and distress for families.

Access is also particularly salient for Indigenous communities. For these communities located in rural or remote areas, geography creates challenges for access to healthcare in general and PPC in particular, since children and family members have to travel significant distances in order to receive care and children may subsequently die far from home. This separation from other family members, such as siblings, and from their community occurs at a time when they most need community support. The separation is even more significant considering the value placed by Indigenous communities on holistic approaches to health, in which “death is not meant to be a medical event” but a moment of community—an instructive posture for western culture and medicine.<sup>51</sup>

<sup>47</sup> Widger et al., “Pediatric Palliative Care in Canada in 2012,” e566.

<sup>48</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence* at 13.

<sup>49</sup> K. Widger et al., “Location of Death among Children with Life-Threatening Conditions: A National Population-Based Observational Study Using the Canadian Vital Statistics Database (2008–2014),” *Canadian Medical Association Journal Open Access* 11, no. 2 (March 2023): e298–304, <https://doi.org/10.9778/cmajo.20220070>.

<sup>50</sup> Widger et al., “Predictors of Specialized Pediatric Palliative Care Involvement,” 804.

<sup>51</sup> M. Anderson and G. Woticky, “The End-of-Life Is an Auspicious Opportunity for Healing: Decolonizing Death and Dying for Urban Indigenous People,” *International Journal of Indigenous Health* 13, no. 2 (2018): 50, <https://doi.org/10.32799/ijih.v13i2.32062>.

More broadly, even for those Indigenous Canadians who live in urban centres, legacies of historical mistreatment within healthcare and ongoing experiences of discrimination can produce mistrust of healthcare institutions and personnel, particularly when it comes to the care of their children. This intensifies the need to ensure that culturally sensitive care is available—particularly amid the illnesses and deaths of children—but difficulty in accessing cultural resources in these contexts remains a concern.<sup>52</sup>

*Access to PPC for Indigenous children is further complicated by “jurisdictional ambiguities,” in which conflict exists between different governments over which is responsible for providing the services—and, importantly, which is responsible for the costs associated with them.*

Access to PPC for Indigenous children is further complicated by “jurisdictional ambiguities,” in which conflict exists between different governments over which is responsible for providing the services—and, importantly, which is responsible for the costs associated with them.<sup>53</sup> These jurisdictional conflicts have resulted in delayed access to the provision of healthcare services, or, in the case of Jordan River Anderson, in the family’s inability to bring their son home to their remote community. Though cleared by his medical team to return home at age two, the dispute between provincial and federal governments over payment for the necessary provision of healthcare services meant that Jordan remained in hospital, far from home, until his death

on his fifth birthday. This case resulted in the creation of Jordan’s Principle by the House of Commons in 2007, which is intended to ensure that the child’s interest, such as facilitating a return home and providing home care, is prioritized above that jurisdictional disputes. Ongoing issues with implementing Jordan’s Principle remain, however, resulting in a 2016 ruling by the Canadian Human Rights Tribunal finding continued discrimination by the Government of Canada toward First Nations and Inuit children and families.<sup>54</sup> Despite a wider use of the Principle since, ongoing issues continue to impact the provision of services for Indigenous children.<sup>55</sup>

These access issues are compounded by the significant and long-standing disparities in health that exist between Indigenous and non-Indigenous Canadians generally.<sup>56</sup>

<sup>52</sup> Anderson and Woticky, “The End-of-Life Is an Auspicious Opportunity for Healing”; C.S. Caxaj, K. Schill, and R. Janke, “Priorities and Challenges for a Palliative Approach to Care for Rural Indigenous Populations: A Scoping Review,” *Health & Social Care in the Community* 26, no. 3 (2018), <https://doi.org/10.1111/hsc.12469>.

<sup>53</sup> Council of Canadian Academies, “The State of Knowledge on Medical Assistance in Dying for Mature Minors,” 2018, 98–100, <https://cca-reports.ca/wp-content/uploads/2018/12/The-State-of-Knowledge-on-Medical-Assistance-in-Dying-for-Mature-Minors.pdf>; Caxaj, Schill, and Janke, “Priorities and Challenges for a Palliative Approach to Care.”

<sup>54</sup> Council of Canadian Academies, “The State of Knowledge on Medical Assistance in Dying for Mature Minors,” 99.

<sup>55</sup> V. Sinha et al., “Substantive Equality and Jordan’s Principle: Challenges and Complexities,” *Journal of Law and Social Policy* 35 (2021): 21–43, <https://doi.org/10.60082/0829-3929.1422>.

<sup>56</sup> K. Schill and S. Caxaj, “Cultural Safety Strategies for Rural Indigenous Palliative Care: A Scoping Review,” *BMC Palliative Care* 18, no. 1 (2019): 1–13, <https://doi.org/10.1186/s12904-019-0404-y>; S. Shahid et al., “Key Features of Palliative Care Service Delivery to Indigenous Peoples in Australia, New Zealand, Canada and the United States: A Comprehensive Review,” *BMC Palliative Care* 17, no. 72 (2018): 1–20, <https://doi.org/10.1186/s12904-018-0325-1>.



Other public health and broader systematic issues have an impact on Indigenous children, including higher rates of birth complications, the increased prevalence of many common childhood diseases and acute and chronic conditions, as well as exposure to contaminants—all health disparities that exist between Indigenous and non-Indigenous infants and children. Taken together, the data suggest worse outcomes for some life-limiting and life-threatening illnesses, and an increased need for Indigenous children to receive PPC upon diagnosis and throughout their medical journey.<sup>57</sup>

Addressing these challenges for PPC in many Indigenous communities also requires attention to significant resourcing issues that can exist, where “scarcity of equipment, staff, financial resources, and basic utility services all preclude the provision of palliative care to Indigenous children.”<sup>58</sup>

## Quality

Quality of palliative care, generally speaking, is difficult to assess comprehensively, since Canada lacks national standards for palliative care, which contributes to assessment problems in both adult and pediatric palliative care.

Although providing only a partial picture, quality is typically assessed based on indicators within three main areas:

- Studies that assess the timing of palliative care, since early integration of PPC is recognized as best practice;
- Studies that assess the location of death, as an indication of quality reflecting the known general preference for death to occur at home, and as an indication that specialist PPC is successful in reducing the frequency and intensity of hospitalization in the last year(s) of life;
- Studies that assess the intensity of intervention and acute care in the last year of life, which can also be evaluated by looking at the use of healthcare resources and associated costs, since higher costs are associated with more acute care. For instance, are children dying within intensive-care units, or in lower-intensity environments such as a hospice or at home?

## Timing of Integration

Early integration of PPC is recognized as a best practice, beginning with the diagnosis of the life-limiting or life-threatening condition. This does not often occur, however.

<sup>57</sup> Bally, Smith, and Burles, “Pediatric Palliative and Hospice Care in Canada,” 262.

<sup>58</sup> Council of Canadian Academies, “The State of Knowledge on Medical Assistance in Dying for Mature Minors,” 99; Caxaj, Schill, and Janke, “Priorities and Challenges for a Palliative Approach to Care.”

In the study from 2012 by Widger et al. mentioned earlier, 51 percent of the children studied who died during 2012 received specialist PPC for less than thirty days, and 25 percent for less than seven days. The study also found that only about one quarter of the children who died in intensive-care units had contact with a PPC team within their last week of life. This is despite the fact that the majority of children dying in these units “had chronic illnesses or conditions present from birth, and thus the possibility of death was likely evident much earlier.”<sup>59</sup> In other words, referral

*Early integration of PPC is recognized as a best practice, beginning with the diagnosis of the life-limiting or life-threatening condition.*

could have occurred significantly earlier. As Widger et al. note, “Delayed referral for these children raises concerns about the adequacy and timeliness of discussions about goals of care and whether families receive all the benefits associated with provision of expert pediatric palliative care.”<sup>60</sup>

Some positive signs in addressing the need for earlier PPC are present, though. One study that focused on rare and complex neurological, metabolic, and chromosomal conditions, in which care and end-of-life planning is rendered more difficult due to the limited knowledge associated with them, noted that most children (88.2 percent) in the study were receiving PPC.<sup>61</sup> Another study, which surveyed pediatric cardiologists’ and respirologists’ on their referral practices to specialist palliative care, found significantly higher referrals for pediatric palliative care than for adults, but while this may indicate improvements in integrating PPC with other forms of medical care and improving clinicians’ knowledge of PPC, this survey data should be compared to actual referral practices to confirm the results.<sup>62</sup>

## Hospitals and Home Care

Given the general preference for death to occur at home, and the reduced difficulty with bereavement as an outcome associated with it, the location of death is an area of study, with a high proportion of at-home deaths considered an indicator of good-quality PPC.<sup>63</sup>

<sup>59</sup> Widger et al., “Pediatric Palliative Care in Canada in 2012,” e566.

<sup>60</sup> Widger et al., “Pediatric Palliative Care in Canada in 2012,” e566.

<sup>61</sup> D. Bao et al., “Charting the Territory: End-of-Life Trajectories for Children with Complex Neurological, Metabolic, and Chromosomal Conditions,” *Journal of Pain and Symptom Management* 61, no. 3 (2021): 451, <https://doi.org/10.1016/j.jpainsymman.2020.08.033>. Of note, however, is that the recruitment of the study included seven Canadian and two US centres and thus was not exclusively Canadian in its focus.

<sup>62</sup> N. Jewitt et al., “Pediatric and Adult Cardiologists’ and Respirologists’ Referral Practices to Palliative Care,” *Journal of Pain and Symptom Management* 64, no. 5 (November 1, 2022): 461–70, <https://doi.org/10.1016/j.jpainsymman.2022.07.011>.

<sup>63</sup> Unfortunately looking at location at death by the numbers will not actually tell researchers how well the location matches the wishes of the children and families. See K. Widger et al., “Indicators Used to Assess the Impact of Specialized Pediatric Palliative Care: A Scoping Review,” *Journal of Palliative Medicine* 22, no. 2 (2019): 199–219, <https://doi.org/10.1089/jpm.2018.0420>.

Overall, however, the fact that the majority of child deaths from life-limiting or life-threatening conditions occur in Canadian hospitals and only a small number at home is seen as a worrying sign. A 2023 study of Canadian data on children aged twenty-nine days to nineteen years who died of life-threatening illnesses between 2008 and 2014 reveals that three quarters (74.2 percent) died in hospital and only 16.1 percent were able to die at home.<sup>64</sup> The researchers note that “variability based on province, income and distance from a tertiary pediatric hospital that persist after adjustment for other variables suggest potential inequities in care across the country.”<sup>65</sup> Children in lower-income families, for instance, had higher odds of a hospital death.

This 2023 study contrasts Canada’s 74.2 percent of children with life-threatening illnesses dying in hospitals against lower proportions in England (65.7 percent) and New Zealand (53.6 percent). And while these countries’ smaller geographical size may help make providing palliative care at home easier, the more substantial resources associated with children’s hospices in England, which also support home-based care and deaths alongside in-house hospice care, and the higher rate of children receiving PPC in New Zealand may also contribute to these lower numbers.<sup>66</sup>

In another study focused on healthcare use and costs for Ontario children at end of life, the authors note, “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 home care.”<sup>67</sup>

The importance of specialist PPC has also been confirmed in certain regions of the country. A 2022 study of Ontario children that compared data from an area with access to specialist PPC to an area with only generalist PPC found that the specialist PPC area had better outcomes, including “fewer total health care days, fewer days in intensive-care units, and lower health care costs in last year of their life, as well as a decreased likelihood of in-hospital death, independent of age, gender, rurality, neighborhood income, and cause of death.”<sup>68</sup>

Hospice access can provide an important option for families when home care is not available or not preferred. Widger et al.’s 2012 study found that “in areas where a pediatric hospice was available, 41.9% of children died in the hospice,” suggesting

<sup>64</sup> Widger et al., “Location of Death among Children with Life-Threatening Conditions.”

<sup>65</sup> Widger et al., “Location of Death among Children with Life-Threatening Conditions,” e300.

<sup>66</sup> Widger et al., “Location of Death among Children with Life-Threatening Conditions,” e301. For the original studies, see E. Chang, R. MacLeod, and R. Drake, “Characteristics Influencing Location of Death for Children with Life-Limiting Illness,” *Archives of Disease in Childhood* 98, no. 6 (2013): 419–24, <https://doi.org/10.1136/archdischild-2012-301893>; D. Gibson-Smith, S. Jarvis, and L. Fraser, “Place of Death of Children and Young Adults with a Life-Limiting Condition in England: A Retrospective Cohort Study,” *Archives of Disease in Childhood* 106, no. 8 (2020): 780–85, <https://doi.org/10.1136/archdischild-2020-319700>.

<sup>67</sup> Widger et al., “Children’s End-of-Life Health Care Use and Cost,” 6–7.

<sup>68</sup> Lysecki et al., “Children’s Health Care Utilization and Cost in the Last Year of Life,” 1037.

that this may be a preference for some families.<sup>69</sup> Unfortunately, free-standing hospices are currently available in only seven urban settings in Canada.

### High-Intensity Interventions and Acute Care

PPC is associated with fewer high-intensity interventions and less acute care at the end of life. As such, researchers examine the prevalence of high-intensity interventions or acute care, with lower use at the end of life being associated with better-quality PPC. This includes assessing the frequency of visits to emergency departments and pediatric intensive-care units as well as deaths that occur in them.

While emergency-department visits may be unavoidable as pediatric palliative patients approach the end of life, higher frequencies of such visits often reflect acute symptoms or significant unmet needs, suggesting issues with the PPC being received.<sup>70</sup> A 2021 study found that over a five-year period, one-third of PPC patients in a Montreal hospital made emergency-department visits, usually presenting with acute symptoms such as respiratory distress, seizures, fever, and pain.<sup>71</sup> Such visits pose a challenge for emergency departments of providing care that aligns with a PPC approach, particularly when advance directives for care may have been signed. As the authors describe, emergency departments are set up to triage and treat very ill patients, but such treatment “may not be appropriate for PPC patients in the end-of-life and may explain why a quarter of PPC patients consulting to our [emergency department] were placed in the resuscitation room.”<sup>72</sup> This suggests a need to improve the integration of PPC within pediatric emergency rooms, “so that PPC patients who present to the [emergency department] receive quick and timely care, adapted to their current health situation, needs, wishes, and desired goals of care.”<sup>73</sup>

A qualitative study undertaken at the same pediatric hospital in Montreal found that their emergency-department personnel often feel unprepared to provide for the continuity of care and specific needs and goals of children nearing the end of life and their families, suggesting a need for improved education and communication between palliative care providers, families, and emergency caregivers.<sup>74</sup> Given that most emergency-room visits take place outside of regular clinic hours, increasing the availability and quality of PPC through integration and education in emergency departments is essential to the improved care of pediatric patients in Canada.

<sup>69</sup> Widger et al., “Pediatric Palliative Care in Canada in 2012,” e567.

<sup>70</sup> N. Gaucher, N. Humbert, and F. Gauvin, “What Do We Know about Pediatric Palliative Care Patients Consulting to the Pediatric Emergency Department?,” *Pediatric Emergency Care* 37, no. 7 (2021): e396–400, <https://doi.org/10.1097/PEC.0000000000001620>.

<sup>71</sup> Gaucher, Humbert, and Gauvin, “What Do We Know about Pediatric Palliative Care,” e398.

<sup>72</sup> Gaucher, Humbert, and Gauvin, “What Do We Know about Pediatric Palliative Care,” e398.

<sup>73</sup> Gaucher, Humbert, and Gauvin, “What Do We Know about Pediatric Palliative Care,” e398.

<sup>74</sup> A.-J. Côté, A. Payot, and N. Gaucher, “Palliative Care in the Pediatric Emergency Department: Findings from a Qualitative Study,” *Annals of Emergency Medicine* 74, no. 4 (2019): 481–90, <https://doi.org/10.1016/j.annemergmed.2019.03.008>.

According to a multi-country study that included Canada, “60% of children admitted to a noncritical care hospital ward and who died during their hospitalization, died in the PICU [pediatric intensive-care unit],” but “palliative care consultation during the hospital admission was independently associated with a lower adjusted odds of dying in PICU.”<sup>75</sup> Worryingly, “65% of patients expected to die did not have a palliative care consultation.”<sup>76</sup> The involvement of PPC can support planning for end of life, and those dying outside of PICU had fewer acute interventions prior to death.<sup>77</sup>

Although more pan-Canadian data is needed, one Ontario-based study provides a sense of the quality of PPC in this province, finding that 35.8 percent of the child deaths in the study’s cohort died in the intensive-care unit and 30.9 percent in the emergency department.<sup>78</sup> The high rates of deaths in acute-care settings in the Ontario study raises concerns about whether Canadian children are receiving sufficient PPC.

Increased availability and quality of PPC would provide benefits to the bottom line of the healthcare system, as well. Children who “currently receive the majority of their end-of-life care in acute care settings [present] 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.”<sup>79</sup>

## Improving Pediatric Palliative Care

Unfortunately, progress in PPC access and quality overall has been “very slow over the last 20 years,” in the words of researcher Widger in testimony before the AMAD committee.<sup>80</sup> Research on PPC does suggest areas where intervention and investment can yield improvements, as discussed in this section.

Rural/urban inequities and gaps need continued investment to implement technologies such as telehealth, to support PPC delivery in rural and home-care contexts.<sup>81</sup> Improving telehealth is, however, contingent on improving high-speed internet access in rural areas.

Investments are also called for in order to address barriers that Indigenous and other minority families may face when navigating the healthcare system. Beyond simply

<sup>75</sup> J. Nicoll et al., “Death and Dying in Hospitalized Pediatric Patients: A Prospective Multicenter, Multinational Study,” *Journal of Palliative Medicine* 25, no. 2 (February 2022): 231, <https://doi.org/10.1089/jpm.2021.0205>.

<sup>76</sup> Nicoll et al., “Death and Dying in Hospitalized Pediatric Patients,” 231.

<sup>77</sup> Nicoll et al., “Death and Dying in Hospitalized Pediatric Patients,” 232.

<sup>78</sup> Widger et al., “Children’s End-of-Life Health Care Use and Cost,” 3–4.

<sup>79</sup> Widger et al., “Children’s End-of-Life Health Care Use and Cost,” 7.

<sup>80</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence* at 13.

<sup>81</sup> P.A. Richardson et al., “Evaluating Telehealth Implementation in the Context of Pediatric Chronic Pain Treatment during COVID-19,” *Children* 8, no. 9 (2021), <https://doi.org/10.3390/children8090764>.

ensuring the availability of PPC, culturally sensitive care should be prioritized by means of education and representation among medical professionals.<sup>82</sup> Further research is also needed into PPC as it is currently experienced within Indigenous and other minority communities. While some research has studied palliative care for adults for these populations,<sup>83</sup> very little of this research has focused specifically on PPC.

Measures to help ensure fuller and earlier access to PPC are also indicated, at the generalist level and at the specialist level. Provider education has been shown to help increase early referrals in particular subfields, such as pediatric cancer care.<sup>84</sup> Strengthening the use of the existing curricula that can provide such education to current practitioners, as well as integrating more palliative care and PPC education into medical-school training, can support earlier referrals to specialist PPC teams. Offering training programs for specialist PPC can also continue to support improvements and build capacity in generalist-level PPC. One such positive step was the establishment in 2017 of the Royal College Subspecialty in Palliative Medicine, with streams for both adult and pediatric palliative medicine.<sup>85</sup> As a result, as of 2023, subspecialty residency programs for pediatric palliative medicine are now offered at three universities: the University of Toronto, the University of Ottawa, and the University of British Columbia.<sup>86</sup>

PPC education could also help to address challenges that generalist clinicians experience, such as how to have difficult conversations about death with children and their families.<sup>87</sup> As noted in one study, although Canadian guidelines urge early conversations about care goals, “this is rarely done when patients are well and stable. Moreover, pediatric healthcare professionals report uneven training in generalist pediatric palliative care and discomfort while communicating with families of children with medical complexity about palliative care.”<sup>88</sup>

<sup>82</sup> E. Sample, C. Mikulic, and A. Christian-Brandt, “Unheard Voices: Underrepresented Families Perspectives of Pediatric Palliative Care,” *Clinical Practice in Pediatric Psychology* 9, no. 3 (2021): 318–22, <https://doi.org/10.1037/cpp0000412>.

<sup>83</sup> G. Johnston, A. Vukic, and S. Parker, “Cultural Understanding in the Provision of Supportive and Palliative Care: Perspectives in Relation to an Indigenous Population,” *BMJ Supportive & Palliative Care* 3, no. 1 (2013): 61–68, <https://doi.org/10.1136/bmjspcare-2011-000122>; Anderson and Woticky, “The End-of-Life Is an Auspicious Opportunity for Healing”; Caxaj, Schill, and Janke, “Priorities and Challenges for a Palliative Approach to Care”; H. Prince et al., “If You Understand You Cope Better with It’: The Role of Education in Building Palliative Care Capacity in Four First Nations Communities in Canada,” *BMC Public Health* 19, no. 1 (2019): 1–18, <https://doi.org/10.1186/s12889-019-6983-y>.

<sup>84</sup> K. Widger et al., “National Impact of the EPEC-Pediatrics Enhanced Train-the-Trainer Model for Delivering Education on Pediatric Palliative Care,” *Journal of Palliative Medicine* 21, no. 9 (2018): 1249–56, <https://doi.org/10.1089/jpm.2017.0532>.

<sup>85</sup> J. Pilkey et al., “Palliative Medicine—Becoming a Subspecialty of the Royal College of Physicians and Surgeons of Canada,” *Journal of Palliative Care* 32, no. 3–4 (2017): 113–20, <https://doi.org/10.1177/0825859717741027>.

<sup>86</sup> Royal College of Physicians and Surgeons of Canada, “Accredited Residency Program,” last modified October 10, 2023, <https://www.royalcollege.ca/ca/en/accreditation-pgme-programs/accreditation-residency-programs/accredited-residency-program-search.html>.

<sup>87</sup> S. Stenekes et al., “Development and Implementation of a Survey to Assess Health-Care Provider’s Competency, Attitudes, and Knowledge About Perinatal Palliative Care,” *Journal of Palliative Care* 34, no. 3 (2019): 151–59, <https://doi.org/10.1177/0825859718790627>.

<sup>88</sup> Côté, Payot, and Gaucher, “Palliative Care in the Pediatric Emergency Department,” 481.

More research on PPC can also help Canada continue to improve practices. For instance, although research has been conducted on the location of death (home versus hospital), research is also needed to compare these outcomes with the preferences of the children and their families. Better inclusion of the voices of children and families is needed in research generally, helping to inform the support provided to patients and families throughout the course of illness and in bereavement.<sup>89</sup>

Knowledge gaps also exist due to the wide array of rare childhood conditions. In the words of researchers Drake and Chang, “Children are ‘therapeutic orphans’ where investigation of treatment options to base management decisions is generally lacking.”<sup>90</sup> The relatively small pool of potential participants makes research on these conditions difficult but expanding the research pool through international collaboration may help.

Critically, the lack of clear, national standards and reporting make assessing the availability and quality of PPC difficult. Researchers describe the necessity of better indicators—particularly indicators of quality—and better understanding the impact of PPC on outcomes.<sup>91</sup> Most recent studies of PPC in Canada have focused on Ontario, and research in other regions and from a pan-Canadian standpoint is needed. Furthermore, the exclusion of the pediatric population from CIHI’s reporting on palliative care also needs to be rectified, as the Canadian Network of Palliative Care for Children has noted.<sup>92</sup> Having adequate data to assess the availability and quality of palliative care for children is essential to inform health policy.

## **Euthanasia for Children in the Context of a PPC “Patchwork”**

Canada is not alone in needing to improve its provision of pediatric palliative care. PPC globally has been described as a “patchwork” of services.<sup>93</sup> The rapid adoption of euthanasia and assisted suicide in Canada, however, makes the issues of accessible and quality pediatric palliative care more critical, as the public conversation has

<sup>89</sup> P.R. Tutelman et al., “Concerns of Parents With Children Receiving Home-Based Pediatric Palliative Care,” *Journal of Pain and Symptom Management* 61, no. 4 (2021): 705–12, <https://doi.org/10.1016/j.jpainsymman.2020.09.007>; J.M.G. Bally et al., “Keeping Hope Possible Toolkit: The Development and Evaluation of a Psychosocial Intervention for Parents of Infants, Children and Adolescents with Life Limiting and Life Threatening Illnesses,” *Children* 8, no. 3 (2021), <https://doi.org/10.3390/children8030218>; Bally, Smith and Burles, “Pediatric Palliative and Hospice Care in Canada”; J.C. Streuli et al., “Impact of Specialized Pediatric Palliative Care Programs on Communication and Decision-Making,” *Patient Education and Counseling* 102, no. 8 (2019): 1404–12, <https://doi.org/10.1016/j.pec.2019.02.011>; J. Tay, K. Widger, and R. Stremler, “Self-Reported Experiences of Siblings of Children with Life-Threatening Conditions: A Scoping Review,” *Journal of Child Health Care* 26, no. 4 (2022): 517–30, <https://doi.org/10.1177/13674935211026113>.

<sup>90</sup> Drake and Chang, “Palliative Care of Pediatric Populations,” 11.

<sup>91</sup> Widger et al., “Indicators Used to Assess the Impact of Specialized Pediatric Palliative Care”; J.Y. Boyden et al., “Measuring Pediatric Palliative Care Quality: Challenges and Opportunities,” *Journal of Pain and Symptom Management* 65, no. 5 (2023): e483–95, <https://doi.org/10.1016/j.jpainsymman.2023.01.021>.

<sup>92</sup> Canadian Hospice Palliative Care Association, “Canadian Network of Palliative Care for Children.”

<sup>93</sup> S. Fowler-Kerry, “Pediatric Palliative Care: A New and Emerging Paradigm,” in *Pediatric Palliative Care: Global Perspectives*, ed. C. Knapp, V. Madden, and S. Fowler-Kerry (Dordrecht: Springer, 2012), 449, [https://doi.org/10.1007/978-94-007-2570-6\\_25](https://doi.org/10.1007/978-94-007-2570-6_25).

begun to consider expansion of MAID for “mature minors,” that is, children deemed capable of consent.<sup>94</sup>

In testimony for the AMAD committee, Widger, a leading expert on PPC in Canada, stated that,

I cannot see how we could allow a mature minor to choose MAID unless all support options are fully explored by a specialized team of health professionals who do this work every day. My greatest fear would be that a 16- or 17-year-old who does not have access to this type of care would be left feeling that MAID is his or her only option.<sup>95</sup>

Widger also noted that, although she hopes that very few minors would request MAID if it becomes legal for them, “I think the number of adults who have taken advantage of MAID is much higher than what we thought it might be when Canada started down this path, so who can say?”<sup>96</sup>

Especially given the problems in existing provision of PPC noted in this report, Canadians must ensure that children with serious illnesses or conditions do not feel that MAID is their only option. Canada must ensure that children can receive the holistic and comprehensive care that supports them to live as fully as possible.

## Conclusion

As indicated by the literature, some improvements have occurred in the provision of pediatric palliative care, including an increase in the number of specialist PPC teams and the number of pediatric hospices operating across Canada. These increases have resulted in higher numbers of Canadian children receiving PPC. Despite these improvements, however, large gaps remain that require attention and redress. A large number of Canadian children facing life-limiting and life-threatening illnesses who would benefit from specialist PPC are still not receiving it. And many of those who do receive this care are receiving it only in the very last month or weeks of life, despite the clear benefits of early integration of PPC at the time of diagnosis of a serious illness or condition. Assessments of PPC quality in Canada also show that the vast majority of children are dying in hospitals—rather than at home—and often in acute-care settings, such as emergency departments and pediatric intensive-care units. Receiving high-intensity interventions in these settings at the very end of life is often at odds with the goals of PPC, because it does not adequately prioritize quality of life and comfort.

<sup>94</sup> Cardus, “Ethical Issues in Euthanasia and Assisted Suicide in Canada,” 2023, <https://www.cardus.ca/research/health/perspectives-paper/ethical-issues-in-euthanasia-and-assisted-suicide-in-canada/>.

<sup>95</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence* at 13.

<sup>96</sup> Canada, Parliament, House of Commons, Special Joint Committee on Medical Assistance in Dying, *Evidence* at 17.



Unfortunately, deficiencies in PPC access and quality are even more pronounced in certain areas, with lower access to PPC correlated to being in a lower-income household, residing in a rural area, and significant disparities in the delivery of PPC between Indigenous and non-Indigenous Canadian children in health outcomes and in healthcare. Given the critical urgency we are faced with in the possible expansion of euthanasia to “mature minors,” it is incumbent upon medical practitioners, policy makers, and legislators to work to eliminate the current patchwork of PPC services, and expand the availability and quality of PPC within Canada, so that every infant, child, youth, and teen, and their families, are enveloped by a holistic model of care throughout their medical journey, from diagnosis to end of life.

*A large number of Canadian children facing life-limiting and life-threatening illnesses who would benefit from specialist PPC are still not receiving it.*

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