CSPCP SCMSP
Canadian Society of Palliative Care Physicians
Société canadienne des médecins de soins palliatifs

NEED FOR BETTER DATA: CSPCP RESPONSE ON CIHI REPORT ON ACCESS TO PALLIATIVE CARE IN CANADA

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The Canadian Society of Palliative Care Physicians (CSPCP) is the national specialty society for Palliative Medicine. CSPCP is committed to the development of national standards, outcome measures and quality indicators to shape palliative care policy in Canada and welcomes the ongoing work of the Canadian Institute for Health Information (CIHI) in furthering this goal. The recently released CIHI report on Access to Palliative Care in Canada[1] demonstrates the challenges, weaknesses and gaps in measuring the quantity and quality of palliative care in Canada. We join with CIHI in calling for improved access and we believe further progress will depend on improvements in measurement in concert with enforceable standards of care.

Limitations in available data

In conducting their 2023 review and the earlier 2017 report, CIHI was faced with enormous limitations, definitional challenges and gaps in available data which they have outlined in the appendices to the Report. Challenges with data involve issues ranging from limited input geographically (ON, AB, BC, Yukon), a long-term care database which "contains little information on the treatments provided outside of major medical treatments" to the hospitalization data which is limited in defining what constitutes palliative care. The limitations of the data set used, as identified in the appendices, make it difficult when trying to generalize across jurisdictions. Combined with 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.

The data indicate that the term 'palliative' is used in some medical /administrative records as a diagnostic/prognostic category without reference to an approach or treatment plan associated with 'palliative care'. Even when it refers to palliative care as a treatment, there is almost never any quality or intensity indicators to assess its adequacy.

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[1] Canadian Institute for Health Information. Access to Palliative Care in Canada, 2023. Ottawa, ON: CIHI; 2023.

The report states that people were defined as palliative if there were indications of palliative care in any care settings in the last year of life without clarifying what those indicators included. It is unclear if this means there was consultation with palliative specialists, aggressive interventions relating to symptom management or revisions of goals of care under the supervision of a generalist palliative care provider or simply a statement in a chart that one is "palliative." Without having clear information on what indicators were used in defining palliative care patients, it becomes impossible to draw conclusions on the *quality* of palliative care received.

In assessing sources derived from administrative discharge data or billing code information, there is a need to assess the bias introduced by financial incentives to report palliative care in some jurisdictions even where no formal palliative care programs exist. There is also a potential bias introduced in that there are provinces which have no billing code information for tracking purposes.

In 2021-22, 58% of those who died (89 000 people) were described in CIHI's data as palliative and received some form of palliative care, representing an increase from 52% reported in 2016-17. Contrasting results are found with a detailed study of palliative care involvement in acute care hospitalization in Ontario from 2012-17 from Webber et al[2] using physician billing codes and other diagnostic codes to determine a hierarchy of palliative care involvement from high (most responsible) to medium (consult to palliative care team but not major reason for admission) to low involvement (some input from a palliative care generalist) or no involvement. Using this hierarchy of involvement, Webber et al found "Applying the hierarchy of inpatient palliative care involvement to all hospitalizations in the last year of life, 4.7% had high palliative care involvement, 13.5% had medium palliative care involvement, 16.7% had low palliative care involvement, and 65.1% had no palliative care involvement." This underscores the fact that coding of indicators may not be reliable in capturing the provision of palliative care services.

Conclusions from the CIHI report

While we appreciate that CIHI has produced an enthusiastic and optimistic portrait of palliative care in Canada while still calling for further improvements, CSPCP does not believe the evidence justifies the conclusion that access to palliative care in Canada is improving. We just don't know. As physicians delivering palliative care, we continue to experience widening gaps in access and quality which have only been aggravated by post-pandemic strains. The need for better measurement is of paramount importance. The Report highlights several areas of persisting concern. While it may be accurate that "a substantial increase from 7% to 13% dying at home were supported by palliative care," it reveals that there is opportunity for improvement. In other words, *87% of those dying at home still do not have access to palliative care support.* Highlighting this in the long-term

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[2] Webber C. Delivery of Palliative Care in Acute Care Hospitals: A Population-Based Retrospective Cohort Study Describing the Level of Involvement and Timing of Inpatient Palliative Care in the Last Year of Life. Journal of palliative medicine 07/2021;24(7):1000-1010. doi: 10.1089/jpm.2020.0056.

care population, the report indicates 19% compared to 6% received palliative care in their last year of life. Once again, this should be used to draw attention to the fact that, in a population with higher rates of frailty and comorbid illness than seen in the general public, *over 80% did not have access to palliative care support*.

An equally concerning statistic indicates that half of patients died within 22 days (about 3 weeks) of being identified as palliative across all settings. When comparing with inpatient populations, this length of time decreases to 11 days. This would represent late involvement rather than earlier identification of needs. Numerous studies demonstrate reduced utilization of aggressive and costly interventions (ICU, ER usage, hospitalizations) in groups where earlier palliative care has been introduced.

This document reports "40% of primary care physicians reported feeling prepared to care for patients with palliative care needs." Once again, reflecting on the fact that 60% do not feel prepared, or face significant difficulties in providing care with a palliative approach, reveals an opportunity to support an earlier introduction. Antonacci et al[3] identify that healthcare practitioners recognize gaps in training experience as a contributing factor to uncertainty in ability to provide palliative and end-of-life care. Enhancing access to educational programs through medical training and in transition to practice can support the development of competencies and confidence in identifying and delivering care to patients with palliative needs.

An Ontario study from 2020[4] found rates of multiple comorbid illnesses as well as higher proportions of age over 85 are being seen with admission demographics in long term care facilities. Along with these comorbid illnesses, residents were seen to have greater challenges, both physical and cognitive, altering their complexity of care. In spite of these challenges, staffing and organizational models remain largely unchanged. CSPCP issued key messages regarding long term care indicating that improving staffing ratios should allow improved support for physical, psychosocial and spiritual concerns[5].
In summary, the 2023 CIHI report can only provide data that is available to them and most of this evidence fails to distinguish and measure the essential components of good palliative care. While we must be cautious in our conclusions, we can join with CIHI in emphasizing that many people in Canada who need palliative care (up to 87% in some settings), still do not have access to it. Together with CIHI, we call on governments to assist us in setting up standards and indicators that allow us to measure need and impact.

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[3] Antonacci R, Barrie C, Baxter S, Chaffey S, Chary S, Grassau P, Hammond C, Mirhosseini M, Mirza RM, Murzin K, Klinger CA. Gaps in Hospice and Palliative Care Research: A Scoping Review of the North American Literature. J Aging Res. 2020 Nov 5;2020:3921245. doi: 10.1155/2020/3921245. PMID: 33204532; PMCID: PMC7661142.

[4] Ng, R., Lane, N., Tanuseputro, P., Mojaverian, N., Talarico, R., Wodchis, W.P., Bronskill, S.E. and Hsu, A.T. (2020), Increasing Complexity of New Nursing Home Residents in Ontario, Canada: A Serial Cross-Sectional Study. J Am Geriatr Soc, 68: 1293-1300. https://doi.org/10.1111/jgs.16394
[5] CSPCP Key Messages on Long Term Care. CSPCP-Key-Messages-LTC-March-2022-FINAL.pdf

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The Canadian Society of Palliative Care Physicians recommends:

1. Clear standards and indicators must be established to reflect provision of high-quality palliative care and these standards must be tied to funding through Accreditation Canada.
2. Increased capacity for provision of palliative care among all healthcare workers through mandated educational opportunities through training and transition into practice.
3. Staffing and organizational models in long term care must reflect the changing and complex needs of our ageing population to ensure timely access to high quality palliative care with support across multiple domains of suffering.

Approved by the CSPCP Board of Directors May 22, 2023