

**UNDERSTANDING THE PROVISION OF END-OF-LIFE
AND PALLIATIVE CARE SERVICES IN ONTARIO**
(APPLIED HEALTH RESEARCH QUESTION):



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CONTEXT

This document highlights the goals and actions necessary to ensure the provision of high quality care to Ontarians at the end of their lives, with a focus on care independent of health care settings. To work on these goals, the Central East LHIN, on behalf of the province of Ontario, submitted an Applied Health Research Question to the Health System Performance Research Network, seeking to understand the current state of palliative and end-of-life care in Ontario.

OBJECTIVES

The purpose of this paper was to assess the ability to identify palliative and end-of-life (EoL) patients in Ontario using administrative datasets held at the Institute for Clinical Evaluative Sciences; and to define and describe the characteristics of identified palliative and end-of-life patients within each of Ontario's major health care settings.

METHODS

A retrospective approach allowed for the consultation of databases such as the Registered Persons Database (RPDB) for deaths, and a set of databases that capture healthcare services provided in hospital, physician offices, other health care institutions, and in the community, to effectively capture cohorts of decedents in Ontario and examine their health care service utilization in the 12 months prior to death, as well as the occurrence of end-of-life designation. A prospective approach aimed to identify individuals with either an end-of-life designation in RAI assessment data, or a palliative care code in billing and/or diagnostic data. This analysis followed identified patients until their death, or until the last date of data availability to identify trends of health system utilization.

FINDINGS

A retrospective examination of decedents' healthcare use in the 12 months prior to death, as well as a prospective/follow-up analysis of the healthcare use of individuals with either an end-of-life designation in assessment data, or a palliative care code in billing/diagnostic data, revealed an increasing dependence on hospital settings for the provision of health care services as one nears the end-of-life, and that a significant stay and death in hospital carries a significant cost burden to the healthcare system. The findings also revealed that a higher proportion of people—substantially larger than the death cohort—received palliative care than were assigned an EoL designation, suggesting that palliative care is commonly coded before the last year of life.

CONCLUSIONS

This work can be foundational for future efforts to improve palliative care in Ontario, and to shift care away from health care institutions. Further work is also required to look at the quality and standardization of the palliative care codes used, including a literature review of any previous studies that have used/examined these codes, and an examination of the distribution of palliative care codes among all recipients, across time.

Because an examination of our analyses revealed that a time period of April 1, 2010 to December 31, 2012 was used to capture palliative care and end-of-life designations for this study, there will be a follow-up AHRQ report to further examine palliative care in Ontario, utilizing a true 12 month retrospective look-back period for each decedent.

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