# Culturally- and Spiritually-Sensitive End-of-Life Care: Exploring Current Knowledge Using a Scoping Review Method

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#### Abstract

Multiple factors influence low uptake of end-of-life (EoL) care and experiences of poor quality of care services by culturally and spiritually diverse groups.

This comprehensive literature review was undertaken by the Canadian Virtual Hospice to create a new tool that will support culturally- and spirituallysensitive EoL care. Funding for the project was provided by the Canadian Partnership Against Cancer. This poster presents findings from an international scoping review of peer reviewed academic publications and grey literature.

The review found that: much of EoL research focuses on decision-making with fewer research studies exploring (in-depth) the experiences of different cultural and religious persons at the end of their life; few interventions aimed to improve culturally- and spiritually-sensitive EoL care; and, interventions largely focused on education for medical and nursing students and health care providers.

#### Introduction

End-of-life (EoL) care requires attention to psychological, social and spiritual needs and supports to help individuals cope with the process of aging, coming to terms with death and dying and to help family members and loved ones cope with bereavement<sup>1</sup>. Research reveals that access to EoL health services and social supports either at home or in hospices is low among ethnic minorities compared to white European groups<sup>2,3</sup>.

Key barriers to EoL care include: cultural differences between health care providers and persons approaching EoL, patients and families4; under-utilization of culturally-sensitive models designed for improved EoL care<sup>5</sup>; language barriers<sup>6</sup>; lack of awareness of cultural and spiritual diversity issues; exclusion of families in the decision-making process<sup>7</sup>; personal racial and religious discrimination<sup>8</sup> and lack of culturally-tailored EoL information to facilitate decision-making and uptake of care for culturally- and spiritually-diverse communities8.

The Canadian Virtual Hospice (virtualhospice.ca), an online palliative care knowledge translation resource, recognized the need for a tool to empower patients and families to access culturally-sensitive EoL care. In order to base the empowerment tool on a comprehensive understanding of the attitudes, behaviours and utilization patterns of EoL care by culturally- and spiritually-diverse groups and associated gaps in practice, delivery of health care services and research, we conducted a comprehensive scoping review.

## Methods

#### Design

Scoping review<sup>9</sup> and thematic analysis<sup>10</sup> of article content.

#### **Data Sources**

Fourteen electronic databases and websites were searched between June-August 2014 to identify English-language peer-reviewed publications and grey literature (including reports and other online resources) published between 2004-2014.

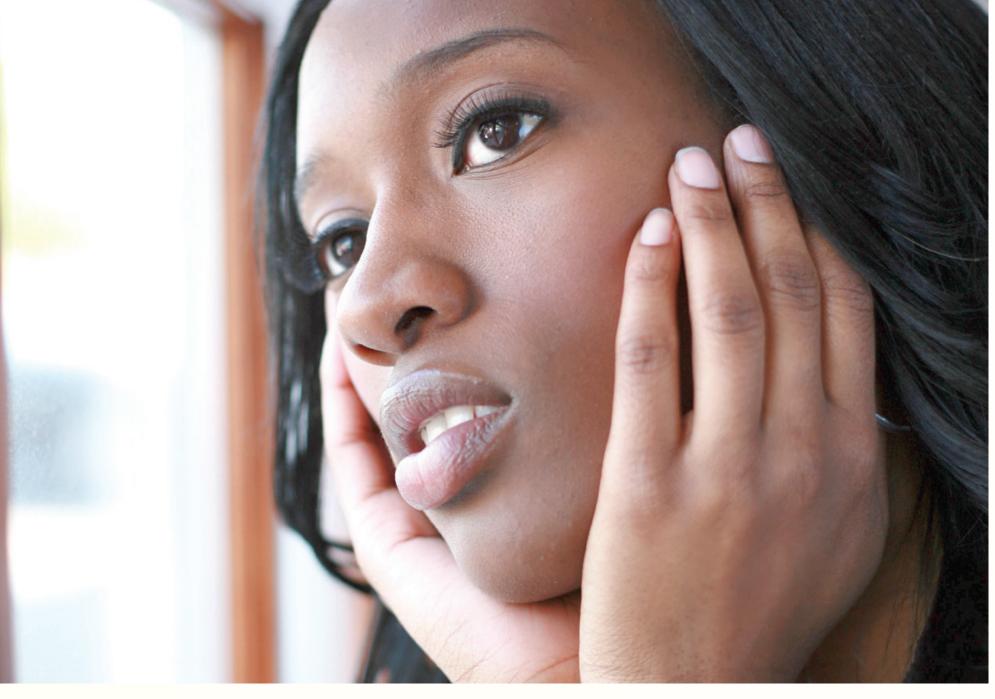
#### Search Strategy

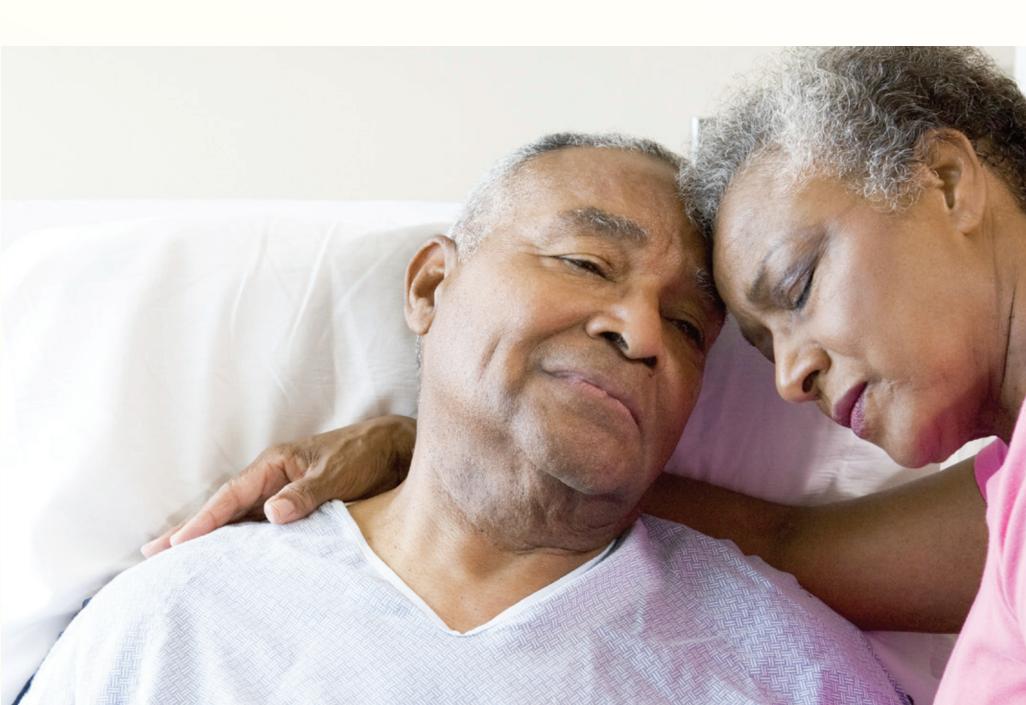
A systematic search of published and unpublished print and digital material focused on barriers and enablers encountered when accessing palliative and end-of-life care. The searches, conducted over 3 months, aimed to capture barriers and enablers at the systems, community and personal/family levels.

The search identified barriers and enablers at the systems, community and personal/family levels. Primary barriers highlighted in the findings include: cultural disconnection between health care providers; persons approaching End-of-life (EoL) and family members; under-utilization of culturally-sensitive models designed for improved EoL care; language barriers; lack of awareness of cultural and religious diversity issues; exclusion of families in the decision-making process; personal racial and religious discrimination and lack of culturally-tailored EoL care information to facilitate decision-making.

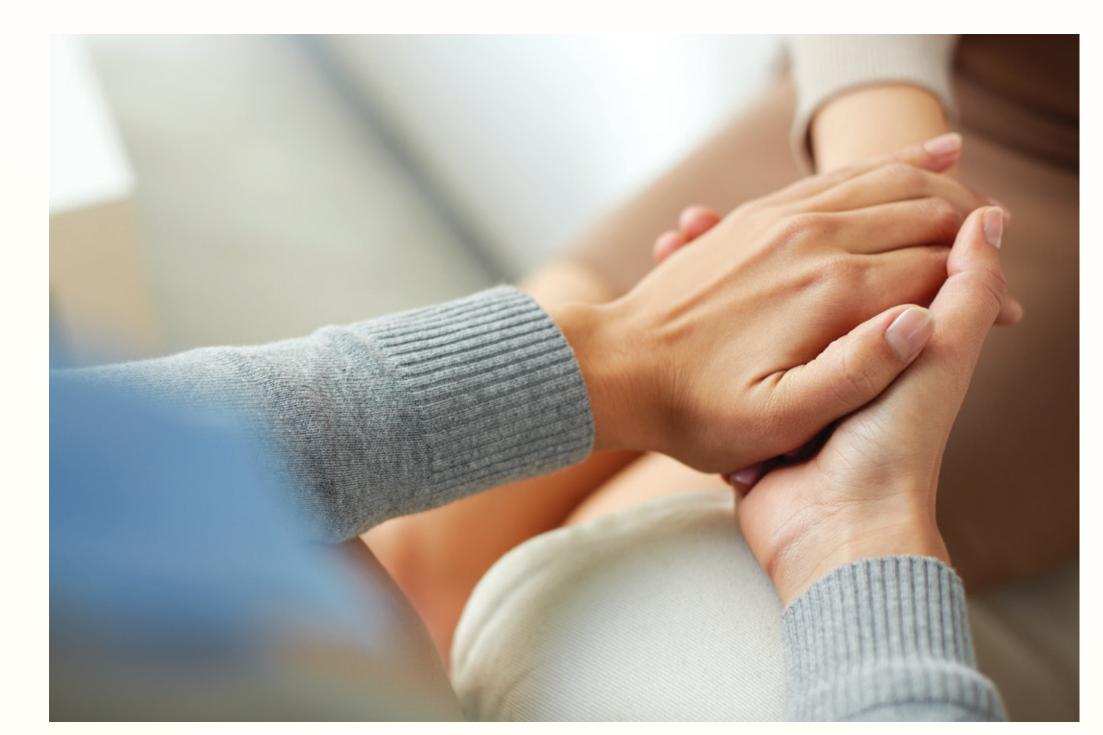
Results

This scoping review established that much of the research has focused on decision-making rather than experiential aspects of care. We found that: fewer research studies explore (in-depth) experiences of different cultural and religious persons at the end of their life; and that interventions aimed to improve culturally- and spiritually-sensitive EoL care were limited.













### Discussion

Although we identified and synthesized a substantial volume of literature, this review is not without limitations. Firstly, our inclusion criteria may have been too broad in scope, which could have contributed to the high quantity and increased heterogeneity of results during the earlier stages of article selection process, namely the title and abstract screening phases. Secondly, only English articles were included and as a result there may be relevant literature on this topic published in other languages.

Primary barriers to End-of-life (EoL) care include cultural differences between health care providers (HCPs), persons approaching EoL and family members; under-utilization of culturally-sensitive models designed for improved EoL care; language barriers; lack of awareness of cultural and spiritual diversity issues; exclusion of families in the decision-making process; personal, racial and religious discrimination and lack of culturally-tailored EoL information to facilitate decision-making and uptake of care for culturallyand spiritually-diverse communities.

Enablers identified in the literature stressed the need for enhanced efforts to: engage family members; incorporate diverse cultural and spiritual values; negotiate with family members the changing needs of the patient to both maintain and release control of the individual's EoL care; and improve and sustain culturally- and linguistically-effective communication between HCPs and service users.

## Conclusions

This scoping review has shown that much End-of-life (EoL) care research has specifically focused on decision-making while everyday service experiences have been relatively neglected in research. Without knowledge of such experiences, it is difficult to ensure that EoL care is delivered in accordance with cultural and spiritual expectations, leaving service users unsatisfied.

While educational interventions are valuable, practice-based interventions were not in evidence; creating a gap in knowledge regarding good practice in home, hospital and hospice settings. Lastly, a substantial proportion of the studies were based in the United States (US). US studies can provide important pointers to high quality culturally- and spiritually-sensitive care in other national contexts; yet, it is important to understand the enablers and barriers to EoL care within a Canadian context if empowerment tools for Canadians from diverse cultural, spiritual, and religious traditions are to be developed.

#### Contact

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