

# End-of-Life Health Care in Ontario: OHTAC Recommendation

Ontario Health Technology Advisory Committee

December 2014

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#### **Conflict of Interest Statement**

All authors in the Evidence Development and Standards branch at Health Quality Ontario are impartial. There are no competing interests or conflicts of interest to declare.

#### **About Health Quality Ontario**

Health Quality Ontario (HQO) is an arms-length agency of the Ontario government. It is a partner and leader in transforming Ontario's health care system so that it can deliver a better experience of care, better outcomes for Ontarians, and better value for money.

Health Quality Ontario strives to promote health care that is supported by the best available scientific evidence. The Evidence Development and Standards branch works with advisory panels, clinical experts, developers of health technologies, scientific collaborators, and field evaluation partners to provide evidence about the effectiveness and cost-effectiveness of health interventions in Ontario.

To conduct its systematic reviews of health interventions, the Evidence Development and Standards branch examines the available scientific literature, making every effort to consider all relevant national and international research. If there is insufficient evidence on the safety, effectiveness, and/or cost-effectiveness of a health intervention, HQO may request that its scientific collaborators conduct economic evaluations and field evaluations related to the reviews. Field evaluation partners are research institutes focused on multicentred clinical trials and economic evaluation, as well as institutes engaged in evaluating the safety and usability of health technologies.

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The Ontario Health Technology Advisory Committee (OHTAC) is a standing advisory subcommittee of the Board of Directors of Health Quality Ontario. Based on the evidence provided by Evidence Development and Standards and its partners, OHTAC makes recommendations about the uptake, diffusion, distribution, or removal of health interventions within the provincial health system. When making its recommendations, OHTAC applies a unique decision-determinants framework that takes into account overall clinical benefit, value for money, societal and ethical considerations, and the economic and organizational feasibility of the health care intervention in Ontario.

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Once finalized and approved by the Board of Directors of Health Quality Ontario, the research is published as part of the *Ontario Health Technology Assessment Series*, which is indexed in MEDLINE/PubMed, Excerpta Medica/Embase, and the Centre for Reviews and Dissemination database. Corresponding OHTAC recommendations and associated reports are also published on the HQO website. Visit <u>http://www.hqontario.ca</u> for more information.

When sufficient data are available, OHTAC tracks the ongoing use of select interventions it has previously reviewed, compiling data by time period and region. The results are published in the Ontario Health Technology Maps Project Report.

#### Disclaimer

This report was prepared by the Evidence Development and Standards branch at Health Quality Ontario or one of its research partners for the Ontario Health Technology Advisory Committee and was developed from analysis, interpretation, and comparison of scientific research. It also incorporates, when available, Ontario data and information provided by experts and applicants to HQO. The analysis may not have captured every relevant publication and relevant scientific findings may have been reported since the development of this recommendation. This report may be superseded by an updated publication on the same topic. Please check the Health Quality Ontario website for a list of all publications: <a href="http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations">http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations</a>.

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# Background

In July 2013, the Evidence Development and Standards (EDS) branch of Health Quality Ontario (HQO) began work on developing an evidentiary framework for end of life care. The focus was on adults with advanced disease who are not expected to recover from their condition. This project emerged from a request by the Ministry of Health and Long-Term Care that HQO provide them with an evidentiary platform on strategies to optimize the care for patients with advanced disease, their caregivers (including family members), and providers.

After an initial review of research on end-of-life care, consultation with experts, and presentation to the Ontario Health Technology Advisory Committee (OHTAC), the evidentiary framework was produced to focus on quality of care in both the inpatient and the outpatient (community) settings to reflect the reality that the best end-of-life care setting will differ with the circumstances and preferences of each client. HQO identified the following topics for analysis: determinants of place of death, patient care planning discussions, cardiopulmonary resuscitation, patient, informal caregiver and healthcare provider education, and team-based models of care. Evidence-based analyses were prepared for each of these topics.

HQO partnered with the Toronto Health Economics and Technology Assessment (THETA) Collaborative to evaluate the cost-effectiveness of the selected interventions in Ontario populations. The economic models used administrative data to identify an end-of-life population and estimate costs and savings for interventions with significant estimates of effect. For more information on the economic analysis, please contact Murray Krahn at murray.krahn@theta.utoronto.ca.

The End-of-Life mega-analysis series is made up of the following reports, which can be publicly accessed at <a href="http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations">http://www.hqontario.ca/evidence/publications-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations/ohtas-reports-and-ohtac-recommendations</a>.

- > End-of-Life Health Care in Ontario: OHTAC Recommendation
- > Health Care for People Approaching the End of Life: An Evidentiary Framework
- > Effect of Supportive Interventions on Informal Caregivers of People at the End of Life: A Rapid Review
- > Cardiopulmonary Resuscitation in Patients with Terminal Illness: An Evidence-Based Analysis
- > The Determinants of Place of Death: An Evidence-Based Analysis
- Educational Intervention in End-of-Life Care: An Evidence-Based Analysis
- > End-of-Life Care Interventions: An Economic Analysis
- > Patient Care Planning Discussions for Patients at the End of Life: An Evidence-Based Analysis
- > Team-Based Models for End-of-Life Care: An Evidence-Based Analysis

The Evidence Development and Standards branch at Health Quality Ontario conducted a mega-analysis<sup>1</sup> on end-of-life (EoL) care comprising 5 evidence-based analyses (1-5) and 1 rapid review<sup>2</sup> (6) to answer the following research questions:

- What are the determinants of place of death in adult patients who have been diagnosed with an advanced, life-limiting condition and are not expected to stabilize or improve?
- Which approaches to patient care planning discussions (PCPDs) optimize the quality of EOL care for patients with advanced disease, informal caregivers, and providers?

<sup>&</sup>lt;sup>1</sup>A mega-analysis is a systematic review of multiple interventions around a health state to assist in comparative decision making.

<sup>&</sup>lt;sup>2</sup>Rapid reviews are developed in response to an urgent need to provide evidence, and in some cases develop OHTAC recommendations, in support of provincial initiatives. Rapid reviews must be completed within a 2- to 4-week time frame and therefore are not as comprehensive as other evidence reports prepared by the Evidence Development and Standards branch at Heath Quality Ontario.

- Do educational interventions in EOL care for health care providers, patients nearing the end of life, or informal caregivers improve the quality of life of patients or informal caregivers compared with usual education?
- Is there an optimal team-based model of care for delivery of end-of-life services? What is the effectiveness of different team-based models on relevant patient, caregiver, health care provider, and system-level outcomes?
- What is the post–cardiopulmonary resuscitation (CPR) survival rate for patients with terminal illness?
- What is the effectiveness of supportive interventions in improving coping and reducing distress for informal caregivers of patients receiving palliative/EOL care?

In addition, Health Quality Ontario commissioned the Toronto Health Economic and Technology Assessment (THETA) Collaborative to evaluate the effectiveness and cost-effectiveness of EOL team care, patient care planning discussions, educational training for patients and informal caregivers, and supportive interventions for informal caregivers. (7)

The summary of the evidence included in the mega-analysis is available in the evidentiary framework document. (8)

# Conclusions

## **Determinants of Place of Death**

On the basis of low-quality evidence, several factors were identified as determinants of place of death:

- interprofessional EOL care in the place of residence
- time between referral to EOL care services and death
- type of underlying disease
- functional status
- frequency of hospitalizations during the last year of life
- living arrangements, such as living with someone
- presence of an informal caregiver
- informal caregiver coping
- patient or family preference for place of death
- existence of advance directives
- nursing home and hospital bed availability
- availability of resources to support the patient's physical and psychological needs in the place of residence during the EOL period

## **Patient Care Planning Discussions**

The best available evidence shows that single-provider and team-based PCPDs provide benefits for patients at the EOL and their families. Discussions earlier in the course of illness are more beneficial than later discussions.

High-quality evidence provides moderate certainty to the conclusion that single-provider PCPDs accomplish the following:

- improve families' satisfaction with EOL care and concordance between patients' and families' wishes;
- reduce the likelihood of receiving hospital care and the number of days spent in hospital;
- increase the completion of advance care planning processes and documents, and the likelihood of receiving hospice care.

Moderate- to high-quality evidence indicates that team-based PCPDs:

- increase patient satisfaction and the completion of advance care planning documents and processes;
- reduce the number of days spent in the intensive care unit and decrease the use of outpatient services.

Finally, moderate-quality evidence shows that earlier PCPDs are associated with receiving less hospital care at the EOL and with receiving more hospice care.

# **End-of-Life Education**

Moderate-quality evidence indicates interventions for health care providers that focus on improving communication skills, knowledge, and attitudes toward EOL care:

- improve symptom control;
- do not improve quality of life (QOL) of informal caregivers, health care providers' satisfaction, or informal caregivers' satisfaction;
- do not reduce resource use including emergency department visits, duration of hospital stay, or admissions to intensive care units.

Low-quality evidence suggests that interventions for health care providers do not improve QOL of patients.

Moderate-quality evidence indicates educational interventions for informal caregivers and patients that focus on symptom management and coping skills:

- improve QOL of informal caregivers;
- improve symptom control;
- do not reduce resource use including emergency department visits, duration of hospital stay, or admissions to intensive care units.

Low-quality evidence suggests that educational interventions for informal caregivers and patients do not improve QOL of patients.

# **Team-Based Model of Care**

## **Comprehensive Team-Based Model**

Moderate-quality evidence indicates that a comprehensive team model that uses direct patient contact to deliver EOL services to patients expected to survive for up to 24 months:

- improves patient QOL, symptom management, and patients' and informal caregivers' satisfaction
- increases the chance of dying at home
- decreases the chance of dying in nursing home
- does not affect hospital admissions or hospital duration of stay

### **Hospital Team-Based Model**

Moderate-quality evidence indicates that a hospital team model of care that uses direct patient contact does not affect length of hospital admissions.

Low-quality evidence suggests that patients receiving hospital EOL team care with direct patient contact have fewer admissions to intensive care units.

## Home Team-Based Model

Low-quality evidence suggests that home EOL team-based care that uses direct patient contact does the following:

- increases patient satisfaction
- increases the number of people who die in their home
- decreases emergency department visits
- decreases hospital admissions

### **Team Membership and Services**

Team membership includes at minimum a physician and nurse, one of whom is specialized or experienced in EOL health care. Team services include the following:

- symptom management
- psychosocial care
- development of patient care plans
- EOL care planning
- coordination of care

## **Cardiopulmonary Resuscitation**

- Recent studies have reported a higher chance of survival after CPR in cancer patients. This finding could reflect the effect of "do not resuscitate" orders in recent years for patients with end-stage cancer.
- Overall, patients with cancer have a lower chance of survival after CPR than patients without cancer.
- The severity of illness in cancer patients can affect survival after CPR. A meta-analysis showed survival-to-discharge of patients with cancer who received CPR in intensive care units was 2.2%, which was one fifth the survival rate of patients with cancer who received CPR in general wards (10.1%), in spite of being monitored in intensive care units.
- Patients with cancer who have cardiac arrest out of hospital and receive CPR either out of hospital or in the emergency department have survival-to-discharge rates similar to hospitalized patients who receive CPR in hospital.
- The type and number of chronic health conditions can affect survival after CPR. Studies showed that patients who had myocardial infarction had better survival-to-discharge after CPR compared with patients who had other health conditions. Patients undergoing hemodialysis had a high chance of survival after CPR.
- Older age is not necessarily a factor in lowering the odds of survival after receiving CPR. However, functional dependence and undergoing multiple CPRs, particularly in advanced age, can reduce the chance of survival after CPR.
- Emergency Medical Services response time affects the chance of survival after out-of-hospital CPR in patients with chronic health conditions.

## **Supportive Interventions for Informal Caregivers**

- Low-quality evidence suggests that direct interventions have a small effect on distress but no effect on coping among informal caregivers of people at the EOL. A more stratified exploration produced moderate-quality evidence indicating that direct interventions for informal caregivers (which combined general advice and support with educational strategies to improve coping and communication skills) were associated with less distress.
- Evidence of very low quality indicates that indirect interventions (interventions provided to the person at the EOL instead of directly to the informal care provider) did not affect distress among informal caregivers.

## **Cost-Effectiveness Analysis**

In-home palliative team care for individuals nearing EOL (at home and in long-term care) reduces expected health care costs and improves health outcomes for patients approaching EOL. The potential effect of this intervention is large, especially the potential for reducing acute care use and improving inhome palliative services.

With respect to the other palliative care interventions we evaluated, firm conclusions are impossible without additional data collected concurrently from patients and their caregivers to update the cost-effectiveness analysis, especially the quality-adjusted life-year calculations.

# **Decision Determinants**

The Ontario Health Technology Advisory Committee (OHTAC) has developed a decision-making framework that consists of 7 guiding principles for decision making and a decision determinants tool. When making a decision, OHTAC considers 4 explicit main criteria: overall clinical benefit, consistency with expected societal and ethical values, value for money, and feasibility of adoption into the health system. For more information on the decision-making framework, please refer to the *Decision Determinants Guidance* document available at <a href="http://www.hqontario.ca/evidence/evidence-process/evidence-review-process/decision-making-framework">http://www.hqontario.ca/evidence/evidence-process/evidence-review-process/decision-making-framework</a>.

Appendix 1 summarizes the decision determinants for this recommendation.

The OHTAC recommendations are developed after considering the decision determinants criteria.

# **OHTAC Recommendations**

The Ontario Health Technology Advisory Committee (OHTAC) recommends that:

- all patients approaching the end of life have access to specialized<sup>3</sup> interprofessional, team-based, integrated care across multiple venues
- patient care planning, including advance care planning and goals of care, be discussed with patients and their informal caregivers early, periodically, and as circumstances change
- evidence about the determinants of place of death be used to inform discussions among patients, informal caregivers, and health care providers regarding the feasibility of patients' dying in their preferred location
- patients and informal caregivers be provided education about symptom management and coping strategies
- education in end-of-life care for health care professionals be provided before and after licensure, and include training on providing supportive care to informal caregivers

With respect to cardiopulmonary resuscitation (CPR), OHTAC recommends that:

- proactive discussions about goals of care inform interventions that could be offered near the end of life
- clinicians routinely discuss not instituting CPR with patients or their substitute decision makers when death can be reasonably anticipated

OHTAC calls for public debate on the normalization and demedicalization of death and dying.

<sup>&</sup>lt;sup>3</sup>A nurse or physician experienced with end-of-life health care.

# Appendices

## **Appendix 1: Decision Determinants**

Table A1:	Determinants	of Place	of Death
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Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical benefit How likely is the health technology/intervention to result in high, moderate, or low overall benefit?	Effectiveness How effective is the health technology/intervention likely to be (taking into account any variability)? Safety How safe is the health	Evidence-based analysis was intended to assess determinants of place of death in an EOL population. Factors related to the illness, individual, and availability of health services were found to affect place of death (GRADE: low) Not evaluated
	technology/intervention likely to be? <b>Burden of illness</b> What is the likely size of the burden of illness pertaining to this health technology/intervention? <b>Need</b>	About 87,000 deaths (<1% of the population) in Ontario each year from 2007–2009 <sup>a</sup> Intermediate impact
	How large is the need for this health technology/intervention?	
Consistency with expected societal and ethical values <sup>b</sup> How likely is adoption	Societal values How likely is the adoption of the health technology/intervention to be congruent with expected societal values?	Patients have the right to express their preferences at the EOL
of the health technology/intervention to be congruent with societal and ethical values?	Ethical values How likely is the adoption of the health technology/intervention to be congruent with expected ethical values?	Patients have the right to express their preferences at the EOL
Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/intervention likely to be?	Not evaluated
Feasibility of adoption into health system	Economic feasibility How economically feasible is the health technology/intervention?	Not evaluated
How feasible is it to adopt the health technology/intervention into the Ontario health care system?	Organizational feasibility How organizationally feasible is it to implement the health technology/intervention?	Determinants of place of death identified might be useful to assess the feasibility of the patient dying in his or her location of preference

Abbreviations: EOL, end of life; GRADE, Grading of Recommendations Assessment, Development, and Evaluation.

<sup>a</sup>Source: Statistics Canada. Deaths in hospital and elsewhere, Canada, provinces and territories, annual, Table 102-0509 (updated September 2013). <sup>b</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical benefit	Effectiveness	Outcomes
How likely is the health technology/intervention to result in high, moderate, or low overall benefit?	How effective is the health technology/ intervention likely to be (taking into account any variability)?	<ul> <li>Single-provider PCPDs may be associated with higher QOL for patients (GRADE: very low), but team-based PCPDs were not associated with patients' QOL (GRADE: moderate). Earlier team-based PCPDs were associated with higher QOL (GRADE: low)</li> <li>There is no evidence that single-provider PCPDs were associated with higher QOL for carers (GRADE: very low)</li> <li>Single-provider PCPDs were associated with patients being "very</li> </ul>
	, , , , , , , , , , , , , , , , , , ,	satisfied" with care received at EOL, but they were associated with lower patient satisfaction when a scale was used (GRADE: moderate). On the other hand, team-based PCPDs were clearly associated with higher patient satisfaction with care (GRADE: high)
		<ul> <li>Single-provider PCPDs were associated with family members being more satisfied with care (GRADE: high)</li> </ul>
		<ul> <li>There is no evidence that single-provider PCPDs were associated with the concordance between patients' wishes and the care they received (GRADE: high), but single-provider PCPDs were associated with higher concordance between patients' wishes and those of their family members (GRADE: high)</li> </ul>
		<ul> <li>Single-provider (GRADE: high) and team-based (GRADE: high) PCPDs were both associated with greater completion of advance care planning documents and processes</li> </ul>
		Health Care Use Outcomes
		<ul> <li>Single-provider PCPDs were associated with a lower likelihood of receiving chemotherapy at EOL (GRADE: low). Further, single- provider PCPDs occurring more than 30 days before death were associated with a lower likelihood of patients receiving chemotherapy at EOL when compared with those occurring 30 days or less before death (GRADE: low)</li> </ul>
		<ul> <li>Single-provider PCPDs were associated with a lower likelihood o patients being resuscitated (GRADE: very low)</li> </ul>
		<ul> <li>Patients who received single-provider PCPDs had 0.2 fewer episodes of hospital care than those who received usual care (GRADE: high), but there was no evidence that team-based PCPDs were associated with number of episodes of hospital care when compared with usual care (GRADE: low)</li> </ul>
		<ul> <li>Earlier single-provider PCPDs were associated with a lower likelihood of patients receiving hospital care when compared with having no discussions (GRADE: moderate)</li> </ul>
		<ul> <li>Single-provider PCPDs were associated with spending 1.8 fewer days in hospital when compared with usual care (GRADE: high). was unclear whether or not there was a relationship between team-based PCPDs and the number of days spent in hospital, however (GRADE: low)</li> </ul>
		<ul> <li>Single-provider PCPDs were not associated with the number of visits to the emergency department when compared with usual care (GRADE: low), and it is unclear whether or not team-based PCPDs were associated with number of visits to the emergency department when compared to usual care (GRADE: moderate)</li> </ul>
		<ul> <li>It is unclear whether or not single-provider PCPDs were associated with admissions to ICUs when compared with having no discussion at all (GRADE: very low). However, the evidence shows that single-provider PCPDs occurring more than 30 days before death were associated with a lower likelihood of patients being admitted to the ICU at EOL than those occurring 30 days or</li> </ul>

### Table A2: Patient Care Planning Discussions

Decision Criteria	Subcriteria	Decision Determinants Considerations
		<ul> <li>less before death (GRADE: low)</li> <li>There was no evidence that team-based PCPDs were associated with the number of days spent in the ICU (GRADE: high)</li> <li>Single-provider PCPDs were not associated with the number of home health visits a patient had when compared with usual care (GRADE: very low)</li> <li>Compared with usual care, team-based PCPDs were associated with fewer urgent care visits (GRADE: moderate)</li> <li>Single-provider PCPDs were not associated with the number of outpatient visits a patient had when compared with usual care (GRADE: low), but team-based PCPDs were associated with fewer outpatient visits than usual care (GRADE: low), but team-based PCPDs were associated with fewer outpatient visits than usual care (GRADE: moderate)</li> <li>Compared with usual care, single-provider PCPDs were associated with fewer outpatient visits than usual care (GRADE: moderate)</li> <li>Compared with usual care, single-provider PCPDs were associated with fewer outpatient visits than usual care (GRADE: moderate)</li> <li>Compared with usual care, single-provider PCPDs were associated with receiving hospice care more frequently (GRADE: high).Compared with having no discussion, these PCPDs were also associated with receiving hospice care for more than 1 week (GRADE: low). Further, earlier single-provider PCPDs were associated with a higher likelihood of receiving hospice care than</li> </ul>
	Safety	were no discussions at all (GRADE: moderate) No safety concerns were identified, but PCPDs can cause distress if they
	How safe is the health technology/ intervention likely to be?	are conducted inappropriately
	Burden of illness What is the likely size of the burden of illness pertaining to this health technology/ intervention?	About 87,000 adults died in Ontario each year from 2007 to 2009. This represents less than 1% of Ontario's population
	<b>Need</b> How large is the need for this health technology/ intervention?	An estimated 65% of the approximately 87,000 people who die in Ontario each year could benefit from PCPDs. This indicates that 56,550 people need PCPDs each year
Consistency with expected societal and ethical values <sup>a</sup> How likely is adoption of the health technology/intervention to be congruent with societal and ethical values?	Societal values How likely is the adoption of the health technology/ intervention to be congruent with expected societal values?	<ul> <li>PCPDs can improve communication between patients, families and friends, and providers, which has the potential to improve the quality of care for patients at the EOL. This is consistent with our societal value to ensure high-quality care for all</li> <li>Patients (and their substitute decision makers) have the right to be informed, which is required for fulfilling the legal requirement for informed consent</li> </ul>
	Ethical values How likely is the adoption of the health technology/ intervention to be congruent with expected ethical values?	PCPDs allow patients, families and friends, and providers to consider multiple elements when planning and making decisions about patient care. Weighing these elements when planning care for each patient is consistent with ethical values

Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/ intervention likely to be?	<ul> <li>Identifying long-term care residents who are at the EOL, establishing care preferences, and early referral to palliative care teams reduces health care costs and can increase days at home</li> <li>Ethics consultations for patients in ICUs with treatment or care plan-related conflicts (among patients, providers, and families) reduce health care costs and can increase days at home</li> <li>Family conferences of sufficient durations for relatives of patients dying in ICUs can improve health outcomes for informal caregivers (i.e., unpaid caregivers, who are usually relatives or friends) at an additional cost. The cost-effectiveness of this intervention is uncertain</li> </ul>
Feasibility of adoption into health system How feasible is it to adopt the health technology/intervention into the Ontario health care system?	Economic feasibility How economically feasible is the health technology/ intervention? Organizational feasibility How organizationally feasible is it to implement the health technology/ intervention?	<ul> <li>Not evaluated</li> <li>In determining the organizational feasibility of the intervention, some points that were considered included these: <ul> <li>PCPDs are typically conducted by existing providers within an organization, so it might be unnecessary to hire additional providers to deliver the intervention</li> <li>Providers could require training in order to deliver PCPDs appropriately without causing psychological or emotional harm to patients and their families</li> <li>A staff person could be needed to co-ordinate team-based PCPDs</li> <li>A method or mechanism for documenting key decisions from PCPDs and making them available to providers in various parts of the health system is needed</li> </ul> </li> </ul>

Abbreviations: EOL, end of life; GRADE, Grading of Recommendations Assessment, Development, and Evaluation; ICU, intensive care unit; PCPD, patient care planning discussion; QOL, quality of life. <sup>a</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical benefit How likely is the health technology/intervention to result in high, moderate, or low overall benefit?	Effectiveness How effective is the health technology/intervention likely to be (taking into account any variability)?	<ul> <li>Education of health care providers and patients nearing EOL and their caregivers: <ul> <li>improves symptom control of patients nearing EOL</li> <li>improves informal caregivers' quality of life</li> <li>(GRADE: moderate)</li> </ul> </li> <li>No safety issues identified</li> </ul>
	How safe is the health technology/intervention likely to be? <b>Burden of illness</b> What is the likely size of the burden of illness pertaining to this health technology/intervention?	<ul> <li>~87,000 adults (&lt;1% of the population) died in Ontario each year from 2007 to 2009</li> <li>~93,000 deaths occurred in Ontario during 2012/2013</li> <li>70% of deaths are due to chronic diseases</li> <li>Need for improving quality of life in EOL population is large</li> </ul>
	<b>Need</b> How large is the need for this health technology/intervention?	Need for improving quality of life in EOL population is large
Consistency with expected societal and ethical values <sup>a</sup> How likely is adoption of the health technology/intervention to be congruent with societal and ethical values?	Societal values How likely is the adoption of the health technology/intervention to be congruent with expected societal values? Ethical values How likely is the adoption of the health technology/intervention to be congruent with expected ethical values?	Right to be informed Right to be informed
Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/intervention likely to be?	Currently available and evaluated educational training initiatives for patients and caregivers are unlikely to be cost-effective
Feasibility of adoption into health system How feasible is it to adopt the health technology/intervention into the Ontario health care system?	Economic feasibility How economically feasible is the health technology/intervention? Organizational feasibility How organizationally feasible is it to implement the health technology/intervention?	<ul> <li>Points to consider:</li> <li>Education is provided routinely to health care providers, so additional resources might not be necessary</li> <li>Might need to incorporate education on EOL care as part of training to health care providers</li> <li>Might need additional staff to co-ordinate education for patients nearing EOL and their caregivers on a regular basis</li> </ul>

### Table A3: Education for Patients, Informal Caregivers, and Health Care Providers at the End of Life

Abbreviations: EOL, end of life; GRADE, the Grading of Recommendations Assessments, Development and Evaluation. <sup>a</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical	Effectiveness	Comprehensive Team Model, Direct Patient Contact, Early Start [CLs]
benefit	How effective is the	<ul> <li>Significant improvement in patients' QOL (GRADE: moderate)</li> </ul>
How likely is the	health	<ul> <li>Significant improvement in symptom management (GRADE: moderate</li> </ul>
health technology/	technology/intervention	<ul> <li>Significant improvement in patients' satisfaction (GRADE: moderate)</li> </ul>
intervention to	likely to be (taking into	<ul> <li>Nonsignificant decrease in hospital admission: 0.84 [0.34, 2.03]</li> </ul>
result in high, moderate, or low	account any variability)?	(GRADE: very low)
overall benefit?		<ul> <li>Significant increase in completion of ACP: 2.86 [1.09, 7.55] (GRADE: low)</li> </ul>
		Comprehensive Team Model, Direct Patient Contact
		<ul> <li>Nonsignificant change in patients' QOL (GRADE: moderate)</li> </ul>
		<ul> <li>Significant increase in informal caregivers' satisfaction (GRADE: moderate)</li> </ul>
		<ul> <li>Significant increase in deaths at home: 1.89 [1.13, 3.16] (GRADE:</li> </ul>
		moderate)
		<ul> <li>Significant decrease in deaths at nursing homes: 0.37 [0.20, 0.67] (GRADE: moderate)</li> </ul>
		<ul> <li>Nonsignificant decrease in hospital admission: 0.90 [0.42, 1.89] (GRADE: moderate)</li> </ul>
		<ul> <li>Nonsignificant decrease in hospital LOS (GRADE: moderate)</li> </ul>
		Comprehensive Team Model, Indirect Patient Contact
		<ul> <li>Nonsignificant change in patients' QOL (GRADE: low)</li> </ul>
		Home, Direct Patient Contact
		<ul> <li>Significant improvement in patients' satisfaction (GRADE: low)</li> </ul>
		<ul> <li>Significant increase in deaths at home: 2.2 [1.30, 3.72] (GRADE: low)</li> </ul>
		<ul> <li>Significant decrease in ER visits (GRADE: low)</li> </ul>
		<ul> <li>Significant decrease in hospital admission: 0.39 [0.24, 0.62] (GRADE: low)</li> </ul>
		Home, Indirect Patient Contact
		<ul> <li>Nonsignificant Increase in completion of ACP: 1.30 [0.58, 2.90] (GRADE: very low)</li> </ul>
		<ul> <li>Nonsignificant difference in ER visits (GRADE: low)</li> <li>Hospital, Direct Patient Contact</li> </ul>
		<ul> <li>Nonsignificant change in patients' QOL (GRADE: low)</li> </ul>
		<ul> <li>Nonsignificant change in symptom management scores (GRADE: low</li> </ul>
		<ul> <li>Nonsignificant change in informal caregivers' satisfaction (GRADE: low Nonsignificant change in informal caregivers')</li> </ul>
		<ul> <li>Nonsignificant increase in completion of ACP: 1.77 [0.48, 16.11] (GRADE: low)</li> </ul>
		<ul> <li>Significant decrease in ICU admission (GRADE: low)</li> </ul>
		<ul> <li>Nonsignificant difference on hospital LOS (GRADE: moderate)</li> </ul>
	Safety	No data; team model that increases continuity of care is believed to be safer
	How safe is the health technology/intervention	
	likely to be?	
	Burden of illness What is the likely size of	<ul> <li>~87,000 adults (&lt;1% of the population) died in Ontario each year from 2007 to 2009</li> </ul>
	the burden of illness pertaining to this health technology/intervention? <b>Need</b> How large is the need for this health technology/intervention?	<ul> <li>~93,000 deaths occurred in Ontario during 2012/2013</li> </ul>
		<ul> <li>70% of deaths are due to chronic diseases</li> </ul>
		<ul> <li>About 30 community-based EOL care teams currently in Ontario</li> </ul>
		<ul> <li>14 Regional Hospice Palliative Care and EOL Care Networks have boundaries corresponding to the boundaries of Ontario's health regions. Membership of each network is broad, with general</li> </ul>

### Table A4: Team-Based Models of Care for End of Life

Decision Criteria	Subcriteria	Decision Determinants Considerations
		palliative care. Networks aim to encourage collaboration and information sharing, with the goal of better co-ordinated client care
Consistency with expected societal and ethical values <sup>a</sup> How likely is adoption of the health technology/ intervention to be congruent with societal and ethical values?	Societal values How likely is the adoption of the health technology/intervention to be congruent with expected societal values? Ethical values How likely is the adoption of the health technology/intervention to be congruent with expected ethical values?	Comprehensive team-based approach aligns with health system values and with Ministry commitments (http://www.health.gov.on.ca/en/public/programs/ltc/21_other.aspx) No data
Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/intervention likely to be?	<ul> <li>Community-based in-home palliative team care and inpatient palliative team care reduces expected health care costs</li> <li>Comprehensive hospital-based palliative team care with care coordination of palliative and home care in the community improves health outcomes at an additional cost. Cost-effectiveness of this intervention is uncertain</li> </ul>
Feasibility of adoption into health system How feasible is it to adopt the health technology/ intervention into the Ontario health care system?	Economic feasibility How economically feasible is the health technology/intervention? Organizational feasibility How organizationally feasible is it to implement the health technology/intervention?	<ul> <li>Team approach highly feasible</li> <li>Degree of comprehensiveness unknown</li> </ul>

Abbreviations: ACP, advance care planning; CL, confidence limit; EOL, end of life; ER, emergency room; GRADE, Grading of Recommendations Assessments, Development and Evaluation; ICU, intensive care unit; LOS, length of stay; Pt, patient; QOL, quality of life. <sup>a</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

		·
Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical benefit How likely is the health technology/intervention	Effectiveness How effective is the health technology/intervention likely to be (taking into account any variability)?	Certain individual disease characteristics are usually associated with less chance of survival to discharge from hospital (e.g., disseminated cancer)
to result in high, moderate, or low overall benefit?	Safety How safe is the health technology/intervention likely to be?	A small percentage of patients may require long-term care because of neurologic deficit after CPR
	Burden of illness What is the likely size of the burden of illness pertaining to this health technology/intervention? Need How large is the need for this health technology/intervention?	In 2009, the top 10 leading causes of death in Ontario were cancer, heart disease, cerebrovascular disease, chronic lower respiratory disease, influenza and pneumonia, intentional self-harm, and kidney disease The National Ipsos-Reid survey in 2012 found that most Canadians have not talked about their wishes for care. The survey found that 86% of Canadians have not heard of advance care planning and that only 46% had a designated substitute decision maker
Consistency with expected societal and ethical values <sup>a</sup>	Societal values How likely is the adoption of the health technology/intervention to be congruent	Debatable
How likely is adoption of the health technology/intervention to be congruent with societal and ethical values?	with expected societal values? <b>Ethical values</b> How likely is the adoption of the health technology/intervention to be congruent with expected ethical values?	Debatable
Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/intervention likely to be?	Decisions should not be guided by the concern that costs could outweigh benefit
Feasibility of adoption into health system	<b>Economic feasibility</b> How economically feasible is the health technology/intervention?	N/A
How feasible is it to adopt the health technology/intervention into the Ontario health care system?	Organizational feasibility How organizationally feasible is it to implement the health technology/intervention?	Affected by whether law permits the change in the current policy

### **Table A5: Cardiopulmonary Resuscitation**

Abbreviations: CPR, cardiopulmonary resuscitation; N/A, not applicable.

<sup>a</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

Decision Criteria	Subcriteria	Decision Determinants Considerations
Overall clinical	Effectiveness	Direct Interventions (Provided Over Multiple Sessions)
<b>benefit</b> How likely is the health technology/intervention to result in high,	How effective is the health technology/ intervention likely to be (taking into account any variability)?	<ul> <li>There was no evidence that interventions designed for the family had an effect on informal caregivers' coping (GRADE: very low) of distress (GRADE: low)</li> </ul>
moderate, or low overall benefit?		<ul> <li>Evidence did not indicate that education and training focused on pain management affected coping among caregivers (GRADE: moderate) or their distress (GRADE: moderate)</li> </ul>
	vanability):	<ul> <li>General advice and support did not appear to affect coping amor informal caregivers (GRADE: low) or their distress (GRADE: low)</li> </ul>
		<ul> <li>Providing general advice and support to informal caregivers, alor with a focus on improving coping strategies, reducing uncertainty and increasing openness about the patient's illness, did not appear to affect informal caregivers' coping (GRADE: moderate) but it improved their distress (SMD [95% CI]: 0.24 [-0.45 to -0.04]) (GRADE: moderate)</li> </ul>
		<ul> <li>Giving informal caregivers general advice and support, training to improve their problem-solving skills, and assistance with caring did not appear to affect their coping (GRADE: moderate)</li> </ul>
		<ul> <li>Providing informal caregivers with strategies to improve sleep divide not appear to affect their level of distress (GRADE: very low)</li> </ul>
		<ul> <li>Overall, interventions provided to informal caregivers directly did not affect their level of coping (GRADE: low) but reduced their level of distress (SMD [95% CI]: -0.15 [-0.28 to -0.02]) (GRADI low)</li> </ul>
		Indirect Interventions
		<ul> <li>Having a nurse co-ordinate care for patients did not appear to affect distress among informal caregivers (GRADE: very low)</li> </ul>
		<ul> <li>Providing team-based inpatient hospice care to patients did not affect informal caregivers' distress (GRADE: very low)</li> </ul>
		<ul> <li>Overall, interventions provided to patients did not affect distress among caregivers (GRADE: very low)</li> </ul>
health ter interventi to be? <b>Burden</b> What is the size of the of illness pertaining health ter interventi <b>Need</b> How larg need for health ter	How safe is the health technology/ intervention likely	Supportive interventions are unlikely to lead to adverse outcomes for informal caregivers, but studies have shown that the absence of supportivinterventions has adverse effects on the health and well-being of informal caregivers
	Burden of illness What is the likely size of the burden of illness pertaining to this health technology/ intervention?	About 87,000 adults died in Ontario each year from 2007 to 2009. This represents less than 1% of Ontario's population
		Between 2007 and 2009, about 35,000 (40%) Ontarians died at home or long-term care facilities. Informal caregivers tend to provide care in both or these settings, so the need for supportive interventions for informal caregivers of patients at the EOL is potentially large

### Table A6: Supportive Interventions for Informal Caregivers

Decision Criteria	Subcriteria	Decision Determinants Considerations
Consistency with expected societal and ethical values <sup>a</sup> How likely is adoption of the health technology/intervention to be congruent with societal and ethical	Societal values How likely is the adoption of the health technology/ intervention to be congruent with expected societal values?	Providing support to informal caregivers could improve the quality of dying and death for people who are at the EOL, because they are more likely to receive adequate support regardless of where they want to die
values?	Ethical values How likely is the adoption of the health technology/ intervention to be congruent with expected ethical values?	Supportive interventions distribute the burdens and rewards of providing informal care more equitably and justly, which increases the ethical acceptability of informal caregiving
Value for money How efficient is the health technology likely to be?	Economic evaluation How efficient is the health technology/ intervention likely to be?	Supportive interventions for informal caregivers of patients at the EOL increase health care costs. The cost-effectiveness of such interventions is uncertain
Feasibility of adoption into health system How feasible is it to adopt the health technology/intervention	Economic feasibility How economically feasible is the health technology/ intervention?	Not evaluated
into the Ontario health care system?	Organizational feasibility	In determining the organizational feasibility of providing the intervention, points that were considered included these:
	How organizationally feasible is it to	<ul> <li>Supportive interventions for informal caregivers will need to be developed, because they might not already exist within some health care organizations</li> </ul>
	implement the health technology/ intervention?	<ul> <li>Health care providers might need to undergo specialized training for providing support to informal caregivers</li> </ul>
	intervention?	<ul> <li>There are many types of informal caregivers, and the duration, frequency, and intensity of care they provide is not uniform. Hence, a "one-size-fits-all" approach might be inappropriate</li> </ul>

Abbreviations: CI, confidence interval; EOL, end of life; GRADE, Grading of Recommendations Assessment, Development, and Evaluation; SMD, standardized mean difference.

<sup>a</sup>The anticipated or assumed common ethical and societal values held in regard to the target condition, target population, and/or treatment options. Unless there is evidence from scientific sources to corroborate the true nature of the ethical and societal values, the expected values are considered.

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