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Best Practice Guideline

MARCH 2020

A Palliative Approach to Care in the Last 12 Months of Life

RNAO
Registered Nurses' Association of Ontario
L'Association des infirmières et infirmiers autorisés de l'Ontario

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In the context of RNAO best practice guideline (BPG) development, the term "conflict of interest" (COI) refers to situations in which an expert panel member or an RNAO staff member's financial, professional, intellectual, personal, organizational or other relationships may compromise their ability to independently conduct this guideline development work. Declarations of COI that might be construed as constituting a perceived and/or actual conflict were made by all members of the RNAO expert panel prior to their participation in guideline development work using a standard form. Expert panel members also updated their COI declaration at the beginning of each in-person guideline meeting. Any COI declared by an expert panel member was reviewed by the RNAO BPG Development and Research Team and expert panel co-chairs. No limiting conflicts were identified. Details regarding disclosures are available at RNAO.ca/bpg/guidelines/palliative-approach-care-last-12-months-life.

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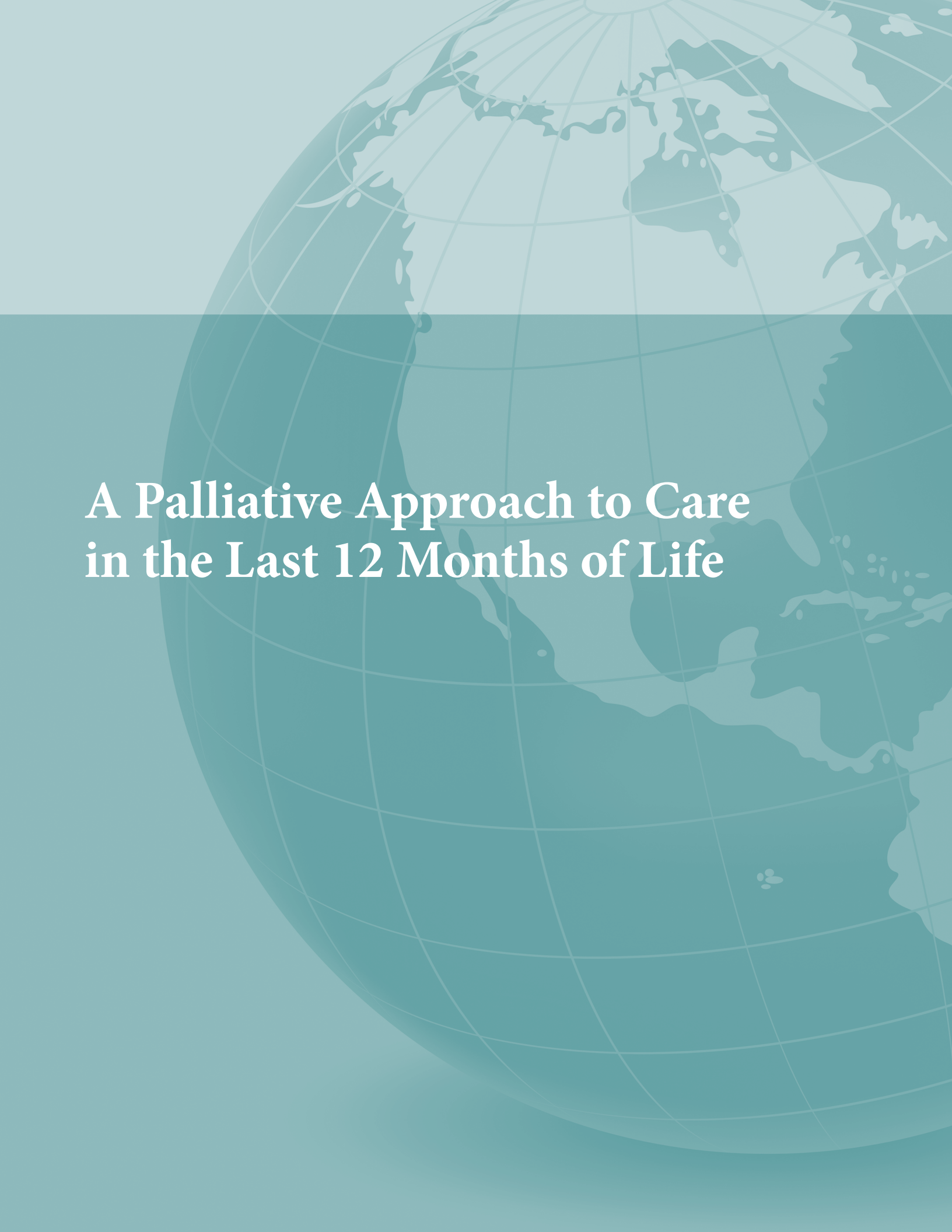


A Palliative Approach to Care in the Last 12 Months of Life

Greetings from Doris Grinspun,

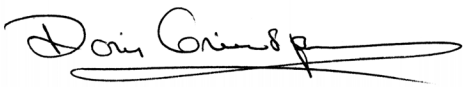
Chief Executive Officer, Registered Nurses' Association of Ontario

The Registered Nurses' Association of Ontario (RNAO) is delighted to present the clinical best practice guideline (BPG) *A Palliative Approach to Care in the Last 12 Months of Life*. Evidence-based practice supports the excellence in service that health providers are committed to delivering every day.

We offer our heartfelt thanks to the many stakeholders who make our vision for BPGs a reality. First, and most important, we thank the Government of Ontario, which recognizes RNAO's capacity to lead a program that has gained worldwide recognition and is committed to funding it. We also thank the co-chairs of the RNAO expert panel, Lesley Hirst (Regional Palliative Care Network Director, Hamilton Niagara Haldimand Brant Local Health Integration Network) and Dr. Christine McPherson (Associate Professor, University of Ottawa), for their invaluable expertise and stewardship of this BPG. Thank you to RNAO staff Zainab Lulat (Guideline Development Lead), Erica D'Souza (Project Coordinator), Grace Suva (Manager, Implementation Science), and the rest of the RNAO Best Practice Guideline Development and Research Team for their intense and expert work in the production of this BPG. Special thanks to the expert panel for generously providing their time, knowledge and perspectives to deliver a rigorous and robust evidence-based resource that will guide the education and practice of many health providers. We couldn't have done it without you!

Successful uptake of BPGs requires a concerted effort from educators, clinicians, employers, policy-makers, researchers and funders. The nursing and health communities, with their unwavering commitment and passion for excellence in patient care, provide the expertise and countless hours of volunteer work essential to the development of new and next edition BPGs. Employers have responded enthusiastically by becoming Best Practice Spotlight Organizations (BPSOs®), sponsoring best practice champions, implementing BPGs and evaluating their impact on patient and organizational outcomes. Governments at home and abroad have joined in this journey. Together, we are building a culture of evidence-based practice that benefits everyone.

We invite you to share this BPG with your colleagues from nursing and other professions, with the patient advisors who are partnering within organizations, and with the government agencies with which you work. We have much to learn from one another. Together, we must ensure that the public receives the best possible care every time they come into contact with us—making them the real winners of this great effort!



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How to Use this Document

This **best practice guideline** (**BPG**)[G]* is a comprehensive document that provides guidance and resources for **evidence-based nursing practice**[G]. It is not intended to be a manual or "how-to" guide; rather, it supports best practices and decision making for **nurses**[G], the **interprofessional health team**[G] and health-service organizations. This BPG should be reviewed and applied in accordance with the needs and **preferences**[G] of adults (18 years and older) who are experiencing the last 12 months of a progressive life-limiting illness and their **families**[G]. This document provides evidence-based **recommendation**[G] statements and descriptions of (a) practice, **education**[G] and organizational considerations, (b) benefits and harms, (c) **values**[G] and preferences and (d) health equity considerations.

Nurses, members of the interprofessional health team and administrators who lead and facilitate practice changes will find this document invaluable for developing policies, procedures, protocols and educational programs to support service delivery. Nurses and members of the interprofessional health team delivering direct care will benefit from reviewing the recommendations and supporting evidence. We encourage practice settings to adapt this BPG into formats that are feasible for daily use.

If your organization is adopting this BPG, we recommend the following steps:

1. Assess your existing policies, procedures, protocols and educational programs in relation to the recommendations and supporting evidence in this BPG.
2. Identify existing needs or gaps in your policies, procedures, protocols and educational programs.
3. Note the recommendations that are applicable to your setting and that can be used to address your organization's existing needs or gaps.
4. Develop a plan for implementing recommendations, sustaining best practices and evaluating **outcome**s[G].

Implementation resources, including the RNAO *Toolkit: Implementation of Best Practice Guidelines, Second Edition* (1), are available at RNAO.ca. For more information, see **Implementation Strategies** on p.84.

All of the RNAO BPGs are available for download, free of charge, on the RNAO website at RNAO.ca/bpg. To locate a particular BPG, search by keyword or browse by topic.

We are interested in hearing your feedback on this BPG and how you implemented it. Please share your story with us at RNAO.ca/contact.

* Throughout this document, terms that are marked with a superscript G ([G]) can be found in the Glossary of Terms (**Appendix A**).

Purpose and Scope

Purpose

RNAO BPGs are systematically developed, evidence-based documents that include recommendations on specific clinical, healthy work environment and health system topics. They are intended for nurses and members of the interprofessional health team in direct care positions, and for educators, administrators and executives, policy-makers, researchers, and **persons**[G] and families with lived experience. BPGs promote consistency and excellence in clinical care, administrative practices, policies, and education, with the aim of achieving optimal health outcomes for people, communities and the health system as a whole.

The purpose of this BPG is to provide evidence-based recommendations to nurses and the interprofessional health team who support adults (18 years and older) experiencing the last 12 months of a progressive life-limiting illness, their families and their caregivers. The goals of the recommendations are to: (a) improve delivery of psychosocial, spiritual and culturally safe care; (b) enhance coordination of care; and (c) facilitate supportive work environments.

The recommendations within this BPG are meant to be implemented as part of a holistic approach to care, as outlined in **Figure 2**: Domains of Issues Associated with Illness and Bereavement (10). It is also in alignment with the aims of **palliative care**[G] (see "Key Concepts Used in This Guideline," p. 7).

Nurses and the interprofessional health team are required to have basic skills, training and competencies in palliative care in order to implement the recommendations of this BPG. For further information, please refer to **Appendix C** (**Education Statements**[G]), the Ontario Palliative Care Network (OPCN) *The Ontario Palliative Care Competency Framework—Nursing Competencies* (summarized in **Appendix K**) and the *Framework on Palliative Care in Canada* (available at https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p2.3.1).

In March 2017, RNAO convened an expert panel to determine the scope of this BPG. The RNAO expert panel was interprofessional in composition, including **family caregivers**[G] and individuals with knowledge and experience in clinical practice, education, research and policy from a range of health-service and academic organizations, practice areas and sectors. Expert panel members shared their insights on supporting and caring for adults with progressive life-limiting illness across the continuum of care (e.g., community, long-term care and acute care). A systematic and comprehensive analysis was completed by the RNAO Best Practice Guideline Development and Research Team and the RNAO expert panel to determine the scope and priority recommendation questions for this BPG (see **Appendix D**).

Scope

To determine the scope of this BPG, the RNAO Best Practice Guideline Development and Research Team conducted the following steps:

- reviewed the RNAO BPG *End-of-life Care During the Last Days and Hours* (2011) (2);
- conducted a search for published guidelines in this topic area and identified gaps in guidance;
- conducted a **scoping review**[G] to determine the breadth and depth of peer-reviewed studies in the area of **Medical Assistance in Dying (MAiD)**[G], with a specific focus on nursing practice;
- interviewed 24 key informants with experience and expertise in the field, including **health providers**[G] in direct care, administrators, researchers and family caregivers; and
- consulted with the expert panel co-chairs and the expert panel in March 2017.

This BPG is applicable to all practice settings where persons and families require palliative care and **end-of-life care**[G] services (e.g., acute care, community care, and long-term care). Specifically, this BPG will focus on persons experiencing the last 12 months of progressive life-limiting illness and their families. It will address the following areas:

- the domains of psychosocial, **spiritual**[G] and **culturally safe**[G] care;
- interprofessional care planning and delivery; and
- strategies to support health providers who provide palliative care and end-of-life care.

The last year of life was chosen as a parameter for this BPG to be consistent with the following sources:

- Ontario Palliative Care Network (OPCN). Palliative care health services delivery framework: recommendations for a model of care to improve palliative care in Ontario. Toronto (ON): OPCN; 2019. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNHSDFRecommendations.pdf
- Wilson JA; Gold Standards Framework. The Gold Standards Framework proactive identification guidance. 6th ed. [place unknown]: Gold Standards Framework; [date unknown]. Available from: https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf

Key Concepts Used in This Guideline

End-of-life care: Care for persons who are expected to die in the foreseeable future and for their families. It includes helping persons and their families prepare for death, ensuring their comfort and supporting decision making that is consistent with the person's prognosis and **goals of care**[G] (3).

Family: "Those closest to the [person] in knowledge, care and affection. The person defines his or her 'family' and who will be involved in his/her care and/or present at the bedside. May include:

- the biological family;
- the family of acquisition (related by marriage/contract); and
- the family of choice and friends (including pets)" (4).

Family caregiver: "Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care" (5).

Health provider: Refers to both regulated workers (e.g., nurses, physicians, dieticians and social workers) and unregulated workers (e.g., personal support workers) who are part of the interprofessional health team.

- **Regulated health provider:** In Ontario, the Regulated Health Professional Act (RHPA), 1991, provides a framework for regulating 23 health professions, outlining the scope of practice and the profession-specific controlled or authorized acts that each regulated professional is authorized to perform when providing health care and services (6).
- **Unregulated health provider:** Unregulated health providers fulfill a variety of roles in areas that are not subject to the RHPA. They are accountable to their employers but not to an external regulating professional body (e.g., the College of Nurses of Ontario). Unregulated health providers fulfill a variety of roles and perform tasks that are determined by their employer and employment setting. Unregulated health providers only have the authority to perform a controlled act as set out in the RHPA if the procedure falls under one of the exemptions set out in the Act (7).

Interprofessional model of care: "Teams with different health-care disciplines working together towards common goals to meet the needs of a patient population. Team members divide the work based on their scope of practice; they share information to support one another's work and coordinate processes and interventions to provide a number of services and programs" (8). In palliative care and end-of-life care, interprofessional health teams include patients, family members, volunteers and family caregivers, along with regulated and unregulated health providers.

Medical Assistance in Dying (MAiD): While there is an intersection between MAiD and palliative care, and each may be part of the person's care path, MAiD and palliative care are both distinctive practices. MAiD specifically refers to "circumstances where a medical practitioner or nurse practitioner, at an individual's request: (a) administers a substance that causes an individual's death; or (b) prescribes a substance for an individual to self-administer to cause their own death" (145).

Palliative care: Palliative care is a philosophy and an approach to care. Palliative care aims to improve the quality of life of persons facing life-limiting illness and their families through the prevention and relief of suffering by means of early identification, assessment and treatment of symptoms (9). It is also referred to as *hospice palliative care*.

Palliative care aims to:

- Relieve suffering and improve the quality of living and dying.
- Address the physical, psychological, social, spiritual (**existential**[G]) and practical issues of persons and their families, and their associated **expectations**[G], needs, hopes and fears.
- Prepare persons and their families for self-determined life closure and the dying process and help them manage it.
- Help families cope with loss and **grief**[G] during the illness and **bereavement**[G] experience.
- Treat all active issues, prevent new issues from occurring and promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization (10).

Person: For the purposes of this BPG, this term refers to those experiencing the last 12 months of progressive life-limiting illness. The term is used interchangeably with patient, resident, and other terms found in the literature.

Topics Outside the Scope of this Best Practice Guideline

- **Advance care planning**[G], grief and bereavement support, palliative care competency requirements, pharmacological interventions and symptom management were considered outside of scope. These subjects have been addressed in recent, evidence-based and credible resources currently in publication and/or in legislation.
  - See **Appendix I** for supporting resources related to pain and symptom management.
  - See **Appendix J** and **K** for supporting resources related to palliative care and end-of-life care education and competency resources.
  - See **Appendix M** for supporting resources related to advance care planning, and grief and bereavement support.
- The scoping review indicated that robust, Canadian-based, peer-reviewed studies that address the role of nurses with MAiD were limited. The role of nurses and MAiD represents an opportunity for future guideline development. In addition, the legislation for MAiD varies between jurisdictions, and this BPG is to be implemented provincially, nationally and internationally.
  - See **Appendix L** for supporting resources related to MAiD.
- Palliative care and end-of-life care for the pediatric population (i.e., infants and children younger than 18 years) is outside the scope of this BPG. The expert panel recognizes that the pediatric population is a unique population with specific considerations for palliative care and end-of-life care. This therefore represents an opportunity for future guideline development.
- This BPG does not address the funding of palliative care and end-of-life care services, although this is an important aspect of every health system and one that governments and government agencies should investigate.

Differences between this BPG and RNAO's *End-of-life Care During the Last Days and Hours* (2011) BPG

This BPG does not replace RNAO's 2011 BPG, *End-of-life Care During the Last Days and Hours*. Rather, the two guidelines differ in the following ways:

- The time frame of this BPG extends beyond the last days and hours of life to include the last 12 months of a progressive life-limiting illness in order to provide recommendations that may be implemented earlier in the palliative care trajectory.
- Based upon the priority recommendation questions and outcomes identified by the expert panel, practice recommendations within this BPG focus on the psychosocial aspect of care; they do not include activities that address physical symptom management. Attention is given to the spiritual, emotional, existential and cultural domains of care, but the recommendations are meant to be implemented as part of a holistic approach to care, as outlined in **Figure 2**: Domains of Issues Associated with Illness and Bereavement (10).

Recommendation Questions

Within the determined scope defined above, the following priority recommendation questions and outcomes were developed by the expert panel. They informed the development of this BPG.

- **Recommendation Question #1:** Should an interprofessional approach be recommended for the provision of care to adults in the last 12 months of life?

  Outcomes: Person and family experience with care; effectiveness of provided care from the person and family perspective; access to care; coordination of care; transitions in care; and effectiveness of provided care from health provider perspective

- **Recommendation Question #2:** What **nurse-led**[G] interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life?

  Outcomes: Support for spiritual care; support for **emotional**[G] care; support for existential care; care in alignment with the person's **wishes**[G]; culturally safe care; place of death

- **Recommendation Question #3:** Should continuing education, targeted skills training and **debriefing**[G] be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families?

  Outcomes: Compassion fatigue[G]; stress/distress; **resilience**[G]

  Note: These priority recommendation questions are condensed versions of the more comprehensive **PICO research questions**[G] (population, intervention, comparison, outcomes) developed by the RNAO expert panel to guide the **systematic reviews**[G] and development of this BPG. For the PICO research questions and the detailed process of how the expert panel determined these priority recommendation questions and outcomes, see **Appendix D**.

Recommendations

Recommendations are presented based on the recommendation question they answer.

The recommendations in this BPG address priority practice and organizational topics identified by the expert panel that relate to caring for adults experiencing the last 12 months of progressive life-limiting illness and their families. These topics include: (a) **interprofessional models of care**[G]; (b) nurse-led interventions related to psychosocial, spiritual and culturally safe care; and (c) continuing education, skills training and debriefing for the interprofessional health team who provide palliative care and end-of-life care.

Note: Recommendations were developed to support care during the last 12 months of life, but some recommendations may be applicable beyond that time frame.

Registered Nurses' Association of Ontario Best Practice Guidelines and Resources that Align with this Best Practice Guideline

Other RNAO BPGs and evidence-based resources may support implementation of this BPG. See **Appendix B** for RNAO BPGs and other resources on the following related topics:

- care transitions;
- crisis intervention;
- constipation;
- delirium, dementia and depression;
- end-of-life care in the last days and hours;
- implementation science, implementation frameworks and resources;
- interprofessional collaboration;
- pain;
- person- and family-centred care;
- pressure injuries; and
- **social determinants of health**[G].

For more information on the guideline development process, systematic review and search strategy for this BPG, see **Appendix D**.

Interpretation of Evidence and Strength of Recommendations

This BPG was developed using an adaptation of the **Grading of Recommendations Assessment, Development and Evaluation (GRADE)**[G] and **Confidence in the Evidence from Reviews of Qualitative Research (CERQual)**[G] methods. For more information about the guideline development process, including the use of GRADE and GRADE-CERQual methods, see **Appendix D**.

Certainty of Evidence

The certainty of evidence (i.e., the level of confidence we have that an **estimate of effect**[G] is true) for quantitative research is determined using an adaptation of GRADE methods (11). After synthesizing the evidence for each prioritized outcome, the certainty of evidence is assessed. The overall certainty of evidence is determined by considering the certainty of evidence across all prioritized outcomes of included studies per recommendation. GRADE categorizes the overall certainty of evidence as *high, moderate, low* or *very low*. See **Table 1** for the definition of these categories.

Table 1: Certainty of Evidence

CERTAINTY OF EVIDENCE	DEFINITION
High	We are very confident that the true **effect**[G] lies close to that of the estimate of the effect.
Moderate	We are moderately confident in the effect estimate: the true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low	Our confidence in the effect estimate is limited: the true effect may be substantially different from the estimate of the effect.
Very low	We have very little confidence in the effect estimate: the true effect is likely to be substantially different from the estimate of effect.

Source: Reprinted from The GRADE Working Group. Quality of evidence. In Schunemann H, Brozek J, Guyatt G, Oxman A, editors. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach [Internet]. [place unknown]: The GRADE Working Group; 2013. Table 5.1, Quality of evidence grades. Available from: https://gdt.gradepro.org/app/handbook/handbook.html#h.wsfivfhuxv4r. Reprinted with permission.

Confidence in Evidence

The confidence in evidence for **qualitative research**[G] (i.e., the extent to which the review finding is a reasonable representation of the phenomenon of interest) is determined using GRADE-CERQual methods (hereafter referred to as CERQual) (12). For qualitative evidence, an overall judgment of the confidence is made per finding in relation to each recommendation statement, as relevant. CERQual categorizes the confidence in evidence as *high, moderate, low* or *very low.* See **Table 2** for the definitions of these categories.

Table 2: Confidence in Evidence

CONFIDENCE IN EVIDENCE	DEFINITION
High	It is highly likely that the finding is a reasonable representation of the phenomenon of interest.
Moderate	It is likely that the finding is a reasonable representation of the phenomenon of interest.
Low	It is possible that the review finding is a reasonable representation of the phenomenon of interest
Very low	It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

Source: Reprinted from Lewin S, Booth A, Glenton C, Munthe-Kass H, Rashidian A, Wainright M et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. Implement Sci. 2018;13(Suppl 1):1-10. Table 3, Description of level of confidence in a review finding in the CERQual approach; p. 6. Reprinted with permission.

The assigned certainty and/or confidence of evidence can be found directly below each recommendation statement. For more information on the process of determining the certainty and/or confidence of the evidence and the documented decisions made by RNAO guideline development methodologists, see **Appendix D**.

NOTE: Due to the complex and multi-faceted nature of palliative care and end-of-life care, the use of **control**[G] groups and the adjustment of **confounding variables**[G] are difficult to achieve. Therefore, the majority of research in this area was from observational or non-randomized studies as opposed to **randomized controlled trials**[G] (which eliminate contextual factors). For this reason, all of the recommendations have a certainty of evidence that is either low or very low. Despite the generally low certainty of evidence, however, the expert panel determined that the benefits, values and preferences for many of the interventions outweighed the potential harms noted in the research evidence or from personal practice experience. As such, the strength of many of the recommendations is strong (see **Strength of Recommendations**). This also highlights the need for more rigorous research in the areas of palliative care and end-of-life care.

Strength of Recommendations

Recommendations are formulated as *strong* or *conditional* by considering the certainty and/or confidence in evidence, and the following key criteria (see the relevant **Discussion of Evidence**, below, for definitions):

- balance of benefits and harms
- values and preferences
- health equity.

Strong Recommendation

A strong recommendation reflects the expert panel's confidence "that the desirable effects of an intervention outweigh its undesirable effects (strong recommendation for an intervention) or that the undesirable effects of an intervention outweigh its desirable effects (strong recommendation against an intervention)" (11). A strong recommendation implies that the majority of persons will be best served by the recommended action (11).

Conditional Recommendation

A conditional recommendation reflects the expert panel's confidence that while some uncertainty exists, the desirable effects probably outweigh the undesirable effects (i.e., a conditional recommendation *for* an intervention) or that the undesirable effects probably outweigh the desirable effects (i.e., conditional recommendation *against* an intervention) (11). A conditional recommendation implies that not all persons will be best served by the recommended action: "there is a need for more careful consideration of personal circumstances, preferences and values" (11).

Note: The strength of the recommendation statement is detailed directly below each recommendation statement and in the **Summary of Recommendations.** For more information on the process the expert panel used for determining the strength of each recommendation, please see **Appendix D.**

Discussion of Evidence

The Discussion of Evidence that follows each recommendation includes the following main sections.

1. **Benefits and Harms:** Identifies the potential desirable and undesirable outcomes reported in the literature when the recommended practice is used. Content in this section solely includes research from the systematic review.
2. **Values and Preferences:** Denotes the relative importance or worth placed on health outcomes from following a particular clinical action from a person-centered perspective. Content for this section may include research from the systematic reviews and, when applicable, observations and/or considerations from the expert panel.
3. **Health Equity:** Identifies the potential impact that the recommended practice could have on health across different populations and/or barriers to implementing the recommended practice in particular settings. This section may include research from the systematic reviews and, when applicable, observations and/or considerations from the expert panel.
4. **Expert Panel Justification of Recommendation:** Provides a rationale for why the expert panel made the decision to rate a recommendation as strong or conditional.
5. **Practice Notes:** Highlights pragmatic information for nurses and members of the interprofessional health team. This section may include supporting evidence from the systematic review and/or from other literature and sources (e.g., the expert panel).

6. **Supporting Resources:** Includes a list of relevant resources (e.g., websites, books and organizations) that support the recommendations. As there are numerous accessible palliative care and end-of-life care resources, this section includes a sample published within the last five to six years and that aligns with the recommendations (with the exception of unique or seminal publications). Content listed in this section was not part of the systematic review and was not quality appraised. As such, the list is not exhaustive, and the inclusion of a resource in one of these lists does not imply an endorsement from RNAO.

Note: Palliative care and end-of-life care legislation can vary between jurisdictions. The supporting resources have been organized to identify resources found within Ontario and those that exist outside of the province.

Summary of Recommendations

RECOMMENDATIONS	STRENGTH OF THE RECOMMENDATION
Recommendation Question #1: Should an interprofessional approach be recommended for the provision of care to adults in the last 12 months of life? **Outcomes:** Person and family experience with care; effectiveness of provided care from the person and family perspective; access to care; coordination of care; transitions in care; effectiveness of provided care from the health provider perspective	
Recommendation 1.1: The expert panel recommends that health-service organizations implement an interprofessional model of care for the provision of palliative care and end-of-life care to persons and families.	Strong
Recommendation 1.2: The expert panel recommends that the interprofessional health team, in collaboration with the person and family, develop an individualized, person-centred plan of care and re-evaluate the plan of care based on the changing status, needs and preferences of the person.	Strong
Recommendation Question #2: What nurse-led interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life? **Outcomes:** Support for spiritual care; support for emotional care; support for existential care; care in alignment with the person's wishes; culturally safe care; place of death	
The following recommendations are applicable within the context of an interprofessional health team (see Recommendations 1.1 and 1.2).	
Recommendation 2.1: The expert panel recommends that nurses assess the cultural needs and values of persons and families.	Strong
Recommendation 2.2: The expert panel recommends that nurses perform ongoing assessments of persons and families for the following: ■ values, beliefs, expectations and preferences about progressive life-limiting illness and death; and ■ preferred place of death.	Strong

Recommendation 2.3: The expert panel suggests that as part of a holistic assessment, nurses assess the spiritual, emotional and existential needs of persons and families, including: ■ concerns about end of life; and ■ presence of spiritual, emotional and existential distress.	Conditional
Recommendation 2.4: The expert panel recommends that nurses address the person's and family's palliative care and end-of-life care expectations.	Strong
Recommendation 2.5: The expert panel suggests that nurses provide opportunities for life reflection to persons and families.	Conditional
Recommendation 2.6: The expert panel recommends that nurses facilitate access to resources, space and services needed by persons and families for cultural, spiritual and/or religious practices.	Strong
Recommendation 2.7: The expert panel recommends that for persons who prefer to die at home, health-service organizations implement high-quality home and community care, which includes: ■ access to after-hours services; ■ care coordination; and ■ support provided by an interprofessional health team.	Strong
Recommendation Question #3: Should continuing education, targeted skills training and debriefing be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families? **Outcomes:** Compassion fatigue; stress/distress; resilience	
The following recommendations are applicable to nurses and the interprofessional health team who provide palliative care and end-of-life care to persons, their families and their caregivers.	
Recommendation 3.1: The expert panel recommends that health-service organizations provide education and skills training for nurses and the interprofessional health team related to self-care, including stress management and mitigation of compassion fatigue.	Strong
Recommendation 3.2: The expert panel recommends that health-service organizations provide time and resources for nurses and the interprofessional health team to engage in debriefing.	Strong

Best Practice Guideline Evaluation

As you implement the recommendations in this BPG, we ask you to consider how you will monitor and evaluate its implementation and impact.

The Donabedian model informs the development of indicators for evaluating quality health care. It includes three categories: structure, process and outcome (13).

- Structure describes the required attributes of the health system, health-service organization or academic institution to ensure quality care. It includes physical resources, human resources, and information and financial resources.
- Process examines the health activities being provided to, for and with persons or populations as part of the provision of quality care.
- Outcome analyzes the effect of quality care on the health status of persons and populations, health workforce, health-service organizations, academic institutions or health systems (13).

For additional information, please refer to the RNAO *Toolkit: Implementation of Best Practice Guidelines, Second Edition* (2012).

It is important to evaluate evidence-based practice changes when implementing a BPG. **Tables 3** and **4** provide potential process and outcome measures to assess BPG success. Select the measures most relevant to the practice setting. The data repositories and indicator libraries available for palliative care and end-of-life care are outlined to support quality improvement and evaluation.

Table 3 supports evaluation of practice changes during implementation. The measures are directly associated with specific recommendation statements and support process improvement.

Table 3: Process Measures for Overall Guideline Success

RECOMMENDATION	PROCESS MEASURES	MEASURES IN DATA REPOSITORIES/ INSTRUMENTS
1.2	Percentage of persons who have a documented person- and family-centered plan of care ***Numerator:*** *Number of persons who have a documented person- and family-centered plan of care* ***Denominator:*** *Total number of persons*	Partial Health Quality Ontario (HQO)

RECOMMENDATION	PROCESS MEASURES	MEASURES IN DATA REPOSITORIES/ INSTRUMENTS
2.1	Percentage of persons with documented assessment of their cultural needs and values ***Numerator:*** *Number of persons with documented assessment of their cultural needs and values* ***Denominator:*** *Total number of persons*	Partial HQO
2.2	Percentage of persons with documented assessment of their preferred place of death ***Numerator:*** *Number of persons with documented assessment of their preferred place of death* ***Denominator:*** *Total number of persons*	Partial HQO
2.4	Percentage of persons with documented discussions regarding their palliative care and end-of-life care expectations ***Numerator:*** *Number of persons with documented discussions regarding their palliative care and end-of-life care expectations* ***Denominator:*** *Total number of persons*	Partial HQO

Table 4 provides potential outcome measures associated with all recommendation statements to assess overall BPG success.

Table 4: Outcome Measures for Overall BPG Success

OUTCOME MEASURES	MEASURES IN DATA REPOSITORIES/ INSTRUMENTS
Percentage of persons whose documentation indicates that they died in their preferred place of death ***Numerator:*** *Number of persons whose documentation indicates that they died in their preferred place of death* ***Denominator:*** *Total number of persons who died*	Health Quality Ontario (HQO)
Percentage of persons who died with documented goals of care ***Numerator:*** *Number of persons who died with documented goals of care* ***Denominator:*** *Total number of persons who died*	New

Other RNAO resources for the evaluation and monitoring of BPGs include the following:

- Nursing Quality Indicators for Reporting and Evaluation® (NQuIRE®), a unique nursing data system housed in the International Affairs and Best Practice Guidelines Centre, allows BPSOs® to measure the impact of BPG implementation by BPSOs worldwide. The NQuIRE data system collects, compares and reports data on guideline-based, nursing-sensitive process and outcome indicators. NQuIRE indicator definitions are aligned with available administrative data and existing performance measures wherever possible, adhering to a "collect once, use many times" principle. By complementing other established and emerging performance measurement systems, NQuIRE strives to leverage reliable and valid measures, minimize reporting burden and align evaluation measures to enable comparative analyses. The international NQuIRE data system was launched in August 2012 to create and sustain evidence-based practice **cultures**[G], optimize patient safety, improve patient outcomes and engage staff in identifying relationships between practice and outcomes to advance quality and advocate for resources and policy that support best practice changes (14). Please visit RNAO.ca/bpg/initiatives/nquire for more information.
- **BPG Order Sets™**[G] embedded within electronic records provide a mechanism for electronic data capture of process and outcome measures. The ability to link structure and process indicators with specific client outcome indicators aids in determining the impact of BPG implementation on specific client health outcomes. Please visit RNAO.ca/ehealth/bpgordersets for more information.

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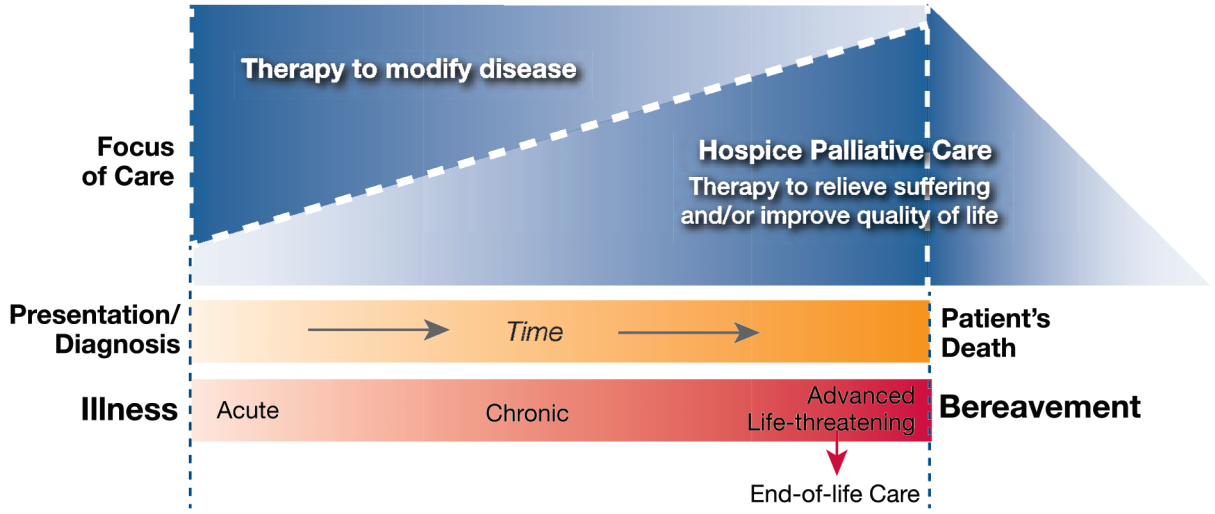
Background Context

What Are Palliative Care and End-of-life Care?

Palliative care refers to a philosophy and an approach to care. Palliative care aims to improve the quality of life for persons facing life-limiting illness and their families through the prevention and relief of suffering. It does this through the early identification, assessment and treatment of symptoms (4). Palliative care extends across the trajectory of life-limiting illness, including care at the point of diagnosis, during treatment and at the end of life, as well as grief and bereavement support (see **Figure 1** for a visual depicting the palliative care trajectory).

Figure 1: A Schematic of the Palliative Care Trajectory



Source: Reprinted from the Canadian Hospice Palliative Care Association (CHPCA). A model to guide hospice palliative care: based on national principles and norms of practice. Revised and condensed edition [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf. Reprinted with permission.

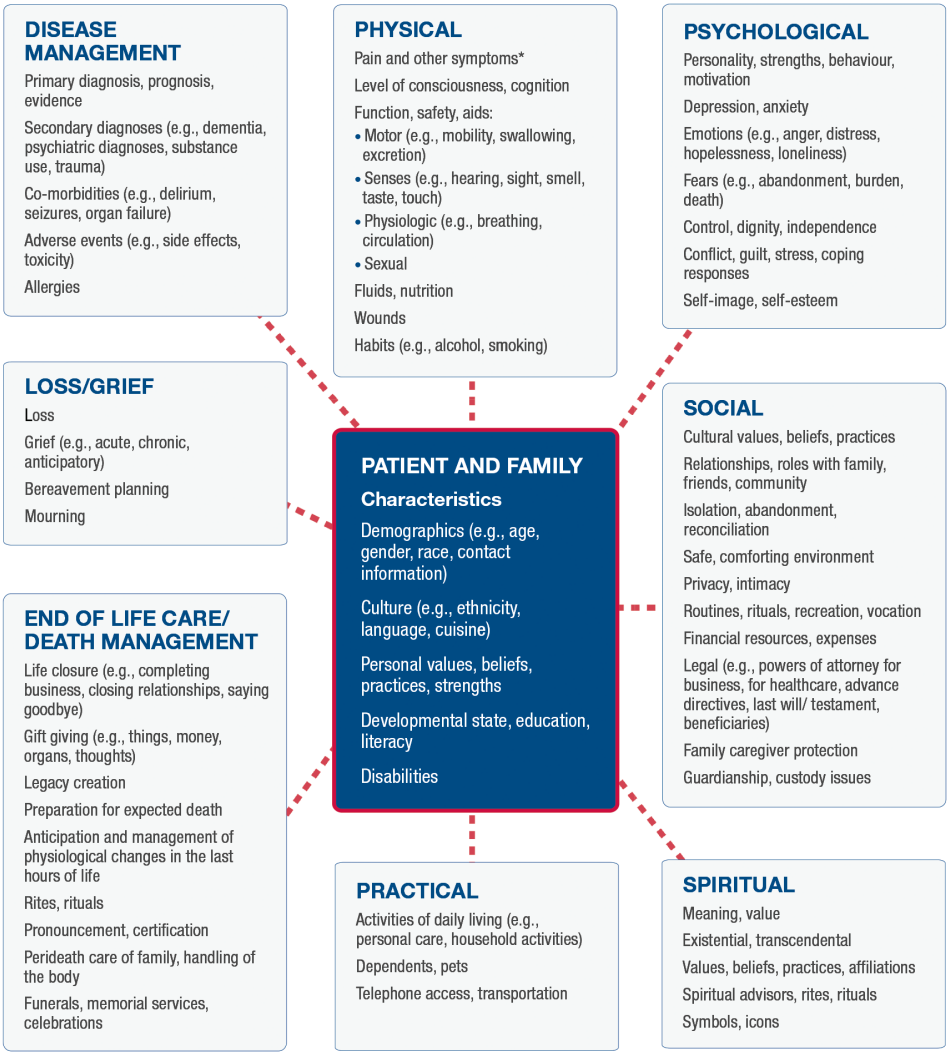
Note: Other models exist that provide visual depictions of palliative care. One example is The Bow Tie Model by Dr. Pippa Halwey. For more information, please visit http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/The+Bow+Tie+Model+of+21st+Century+Palliative+Care.aspx

According to the CHPCA, palliative care (also referred to as "hospice palliative care") is an approach to care that aims to do the following:

- Relieve suffering and improve the quality of living and dying.
- Address the physical, psychological, social, spiritual (existential) and practical issues of persons and their families, and their associated expectations, needs, hopes and fears.
- Prepare persons and their families for self-determined life closure and the dying process and help them manage it.
- Help families cope with loss and grief during the illness and bereavement experience.
- Treat all active issues, prevent new issues from occurring and promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization (10).

Based on these key aims, the recommendations within this BPG focus on quality of life, emphasizing a holistic approach to care that incorporates the person's individuality and preferences, and that recognizes the person and family as the unit of care. **Figure 2** identifies complex issues persons and their families may face when receiving palliative care, which are categorized into eight equally important domains (10).

Figure 2: Domains of Issues Associated with Illness and Bereavement



* Other common symptoms include, but are not limited to:

Cardio-respiratory: breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia

Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

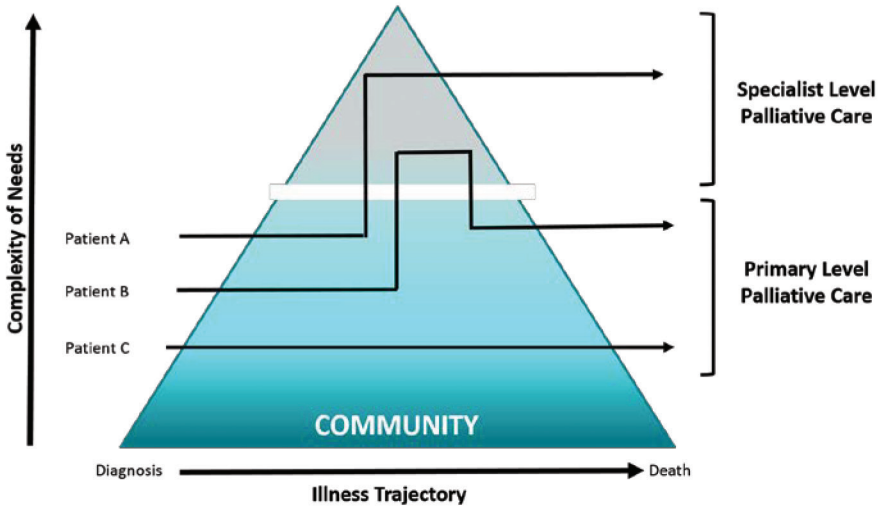
Source: Reprinted from the Canadian Hospice Palliative Care Association (CHPCA). A model to guide hospice palliative care: based on national principles and norms of practice. Revised and condensed edition [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf. Reprinted with permission.

End-of-life care is a component of the palliative care trajectory, and it specifically refers to care for persons who are expected to die in the foreseeable future and their families (refer to **Figure 1**). It includes helping persons and families prepare for death, ensuring their comfort and supporting decision making that is consistent with the person's prognosis and goals of care (3).

Delivery of Palliative Care and End-of-life Care

The delivery of palliative care and end-of-life care is based on comprehensive and ongoing assessment of the needs of persons and families, along with their wishes and preferences (15). Depending on where the person is along the illness trajectory, considerable variability exists with respect to the type and level of care and the services that are required from health providers. See **Figure 3** for a model depicting the illness trajectory, complexity of needs and level of service. For more information regarding the trajectories of illnesses, please refer to the *Gold Standards Framework Proactive Identification Guidance*, available at https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf.

Figure 3: Primary Level and Specialist Level Palliative Care



Source: Reprinted from Ontario Palliative Care Network (OPCN). Key palliative care concepts and terms [Internet]. Toronto (ON): OPCN; 2017. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/KEY_PALLIATIVE_CARE_CONCEPTS_AND_TERMS.pdf. Reprinted with permission.

The majority of persons and families will receive palliative care from primary care clinicians and non-specialist palliative care providers (Patient C in **Figure 3**). Complex issues facing persons and families may require the involvement of specialist palliative care teams, such that a consultation and shared care approach is used to assist non-specialist palliative care providers in delivering care (Patient B in **Figure 3**). In a smaller number of cases, complex palliative care needs may necessitate the transfer of care to specialist palliative care teams (Patient A in **Figure 3**).

As the needs of persons and families are multi-faceted, palliative and end-of-life care are most effective when delivered by an interprofessional health team that is knowledgeable and skilled in palliative care and end-of-life care (10). The interprofessional health team consists of regulated and unregulated care providers, as well as volunteers, family caregivers, and persons and their families.

Access to Palliative Care and End-of-life Care

Palliative care and end-of-life care are appropriate for any person and their family living with (or at risk of) developing a progressive life-limiting illness. In other words, persons facing any diagnosis—regardless of prognosis and age—who have unmet needs and/or expectations can have palliative care and end-of-life care when they are ready to accept it. It is important for persons to receive palliative care as early as possible along their illness trajectory. Compared to late palliative care initiation, early access to palliative care has been found to be associated with improved end-of-life outcomes and lower odds of using acute care services (22). Despite this, access to palliative care services is not equitable across Canada (16). For example, of the persons who died in Ontario in the 2014/15 calendar year, only 57 per cent received at least one palliative care service, while 40.5 per cent did not receive any palliative care services (17). Of those who did receive palliative care, the majority (60.6 per cent) only received care within the last one to two months of life (17). Across disease groups, a report from the Canadian Institute for Health Information (CIHI) found that persons with cancer are three times more likely to receive palliative care than others, and adults aged 45 to 74 years are more likely than younger adults and older adults to receive palliative care across most care settings (16).

A major barrier to access of palliative care and end-of-life care services is cost. For example, the average cost of end-of-life care per person in the last year of life is greater than $50,000 in Ontario, with inpatient care and long-term care representing a substantial portion of total end-of-life care costs (23). For Ontarians receiving palliative care services within the **home**[G], the total cost has been estimated to be approximately $25,000 per month, with $17,500 per month due to lost wages and leisure time for caregivers (17). Not surprisingly, these home-based palliative care services are less likely to be used by persons living in the poorest neighbourhoods compared to those living in the wealthiest neighbourhoods (17). Therefore, funding models to support equitable access to palliative care and end-of-life services are an important aspect of every health system and one that government and government agencies need to address.

Inequitable access to palliative care and end-of-life care services is perhaps most prominent for persons who are **structurally vulnerable**[G] (e.g., persons who are experiencing homelessness) who tend to have inequitable access due to social, economic and environmental factors (18). A systematic review found that barriers to providing care to persons experiencing homelessness and who were seriously ill included: a small social network and lack of support from family and friends, limited insight into their health, living on a "day-to-day" basis with end of life not being a priority, and the **belief**[G] that health providers do not have the knowledge and skill to meet their palliative and end-of-life care needs (187). Although the recommendations in this BPG are clinically applicable to all populations, a fundamental barrier to their implementation is the inequitable access to palliative care and end-of-life care services across all populations. For that reason, awareness and capacity to provide care to diverse populations, inclusive of principles of culturally safe and trauma-informed approaches, remains a priority in palliative care and end-of-life care.

For more information regarding social determinants of health, please refer to the RNAO *Social Determinants of Health Brochure*: RNAO.ca/sites/rnao-ca/files/rnao_sdh_brochure_2013.pdf. For more information regarding Ontario's action plan for access to equitable palliative care, please refer to the *Ontario Palliative Care Network Action Plan* 1: 2017-2020: www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNActionPlan1.pdf.

Psychosocial Needs of Health Providers

Health providers who work in palliative care and end-of-life care are often faced with highly emotional situations. When health providers regularly encounter pain, suffering, death and grief, this can manifest in compassion fatigue and stress (24, 25). Compassion fatigue is a state of "physical and mental exhaustion and emotional withdrawal experienced by those that care for sick or traumatized people over an extended period of time" (26). Recent literature indicates that 52.55 per cent of nurses experience compassion fatigue (27).

Long-lasting compassion fatigue has been linked to negative outcomes at the individual and organizational levels. For the individual health provider, ongoing compassion fatigue may result in: increased fatigue; feelings of hopelessness, frustration and despair; negative impacts on personal relationships; and thoughts of leaving the profession (28, 29). At the organizational level, compassion fatigue may result in high staff turnover rates and increased staff shortages (25, 30). High turnover is linked to significant financial costs for the organization, and most importantly, to adverse patient outcomes (31, 32).

In order to mitigate the negative consequences related to compassion fatigue and stress, strategies to develop resilience and self-care for health providers are required. Resilience refers to a person's ability to thrive in the face of stress and traumatic experiences (33). Increased resilience is associated with improved health, well-being and job satisfaction for health providers; by developing resilience and self-care strategies, they can proactively recognize and mitigate signs of compassion fatigue and stress (24). Health-service organizations also have a responsibility to create environments that promote resilience through interventions that focus on education and skill-building for self-care (24, 34, 35).

Conclusion

This BPG provides evidence-based best practice recommendations for health-service organizations, nurses and members of the interprofessional health team to support adults (18 years and older) who are experiencing the last 12 months of progressive life-limiting illness, their families and their caregivers.

Recommendations

RECOMMENDATION QUESTION #1:

Should an interprofessional approach be recommended for the provision of care to adults in the last 12 months of life?

Outcomes: Person and family experience with care; effectiveness of provided care from the person and family perspective; access to care; coordination of care; transitions in care; effectiveness of provided care from the health provider perspective

RECOMMENDATION 1.1:

The expert panel recommends that health-service organizations implement an interprofessional model of care for the provision of palliative care and end-of-life care to persons and families.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Within the literature, interprofessional models of care consisting of varying team compositions were explored within diverse health settings. An interprofessional model of care refers to a team of different health providers (regulated and unregulated) working together towards a common goal to meet the needs of a patient population. Within this model, team members divide the work based on their scope of practice, sharing information to support their respective work and coordinating processes and interventions to provide a number of services and programs (8). In palliative care and end-of-life care, the person and family are included as key members of the interprofessional health team.

Evidence suggests that interprofessional models of care may improve: (a) the effectiveness of care from the perspective of persons, families and health providers; (b) the experience that a person and their family have with care; and (c) the coordination of care.

Effectiveness of Care from the Perspective of Persons, Families and Health Providers

The effectiveness of interprofessional models of care from the perspective of the person and/or their family has been reported in the literature. An interprofessional model of care has the potential to improve the experiences of care for persons and families through increased satisfaction and improved care (36). For example, patients at an interdisciplinary palliative care out-patient clinic felt that interprofessional care: (a) increased the frequency and timeliness of symptom assessments; (b) improved the person's understanding of medications, side effects and pain management; and (c) ultimately supported enhanced symptom management and **care coordination**[G] (37).

Evidence suggests that health providers also may find interprofessional models of care to be effective. For example, interprofessional health teams may support stronger relationships with the person and family, and they may aid in reducing power imbalances between the interprofessional health team, the person and their family (38). Health providers also report that interprofessional collaboration can promote greater productivity, flexibility and shared responsibility, enabling them to achieve the person's care goals (39). In one study, four health provider groups (physicians, nurses, social workers and spiritual care providers) felt positively about interprofessional collaboration and rated their hospice work environments as supportive. However, social workers reported feeling less valued and connected to other members of the interprofessional health team (38).

Person and Family Experience with Care and Coordination of Care

Interprofessional models of care also may affect the experience that persons and families have with the care they receive. Interprofessional care may increase psychological support and support for daily living activities for the person while decreasing caregiver burden and anxiety (40). Persons and families also report increased satisfaction with care and improved quality of life when receiving care from a specialized out-patient palliative care team (40, 41).

With respect to experiences with care and coordination of care, qualitative evidence suggests that persons with a progressive life-limiting illness and their families who are cared for by an interprofessional health team report: (a) improved continuity of care and holistic care; and (b) increased feelings of security, timely care and responsiveness of health providers when accommodating changing conditions (42).

Although there are findings to support the improved experiences of persons and families with care and the increased coordination of care that are linked to interprofessional models of care, one study demonstrated that communication with health providers may not be enhanced by an interprofessional model of care (40).

Values and Preferences

An interprofessional model of care was positively received, both from the perspective of persons and from health providers (39–41). Health providers who engaged in interprofessional rounds for palliative care reported that the approach facilitated communication and added value to patient care without increasing burden (44).

Health Equity

The expert panel acknowledged that across health-service organizations, there may be inequitable access to the health human resources required to implement interprofessional models of care in an effective way. In rural and remote areas, access to certain health provider groups is limited due to the lower number of health providers employed in these areas (45). As an alternative, the expert panel suggests that telemedicine can be used to support increased access to an interprofessional health team, including in rural and remote geographical areas. The authors of one study outlined the benefits of including a telephone service to increase accessibility to interprofessional models of care, particularly for individuals living in remote areas (37).

Expert Panel Justification of Recommendation

The expert panel attributed value to the interprofessional model of care, wherein interprofessional health teams practice with a shared purpose to provide holistic person- and family-centered care. The expert panel determined that the benefits of interprofessional care outweighed the harms, and that persons experiencing the last 12 months of progressive life-limiting illness would value improvements in the effectiveness, coordination and experiences of

the care they received. Despite the fact that there was a low certainty of evidence and low confidence in the evidence, there were several benefits identified to having an interprofessional approach to care, and few harms were reported. For that reason, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- Interprofessional health teams vary in composition, depending on the health setting (e.g., hospice, acute care, home care or long-term care), so the exact composition of team members required for interprofessional palliative care and end-of-life care is context-dependent and based on the needs of the person receiving care and their family. Regardless, each team member's role should be clearly communicated within the interprofessional health team, as clarity of roles facilitates the provision of coordinated care (47).
- Within the research literature, interprofessional health teams who provide palliative care and end-of-life care services generally include a combination of regulated and unregulated health providers, such as:
  - nurses;
  - physicians;
  - social workers (37, 39, 41, 42, 48–52);
  - paramedical staff (50);
  - advanced practice nurses (41);
  - clinical pharmacy specialists;
  - chaplains (37, 51);
  - dieticians;
  - physical therapists (42, 52, 53);
  - psychologists (49);
  - occupational therapists (42);
  - personal support workers (39);
  - administrative staff;
  - case managers/care coordinators;
  - staff from other collaborating organizations; and
  - family members (54).
- The expert panel further notes that nurse practitioners, volunteers, Indigenous spiritual/traditional healers, elders and medicine persons are key members of the interprofessional health team.
- The expert panel highlighted the importance of clear and ongoing communication between interprofessional health team members, the person and the family. Clear and ongoing communication promotes a mutual understanding of the person's goals of care and avoids potential distress resulting from persons and families having to repeat information to multiple interprofessional health team members.
- It is important for health-service organizations to provide access to and support the use of documentation systems that enable equal access to and timely sharing of information between interprofessional health team members.

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Government of Ontario. Advancing high quality, high value palliative care in Ontario: a declaration of partnership and commitment to action [Internet]. Toronto (ON): Queen's Printer for Ontario; 2013. Available from: http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf	■ Plan for palliative care in Ontario. ■ Discusses virtual extended inter-professional teams.
Health Quality Ontario (HQO). Palliative care: care for adults with a progressive, life-limiting illness [Internet]. Toronto (ON): Queen's Printer for Ontario; 2018. Available from: https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf (English) https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-fr.pdf (French)	■ Quality standard addressing palliative care for people living with a serious life-limiting illness, and for their family and caregivers. ■ Quality Statement 12 focuses on interdisciplinary team-based care.
Ontario Palliative Care Network (OPCN). Palliative care health services delivery framework [Internet]. Toronto (ON): OPCN; 2019. Available from: https://www.ontariopalliativecarenetwork.ca/en/healthservicesdeliveryframework (English) https://www.ontariopalliativecarenetwork.ca/fr/etablissementcadreprestationsoinssante (French)	■ Model of care for adults with a life-limiting illness who are living at home or in community settings and for their families and caregivers. ■ Designed to enable care to be delivered according to the quality standard for palliative care. ■ Discusses interdisciplinary team-based palliative care.

RESOURCE	DESCRIPTION
Registered Nurses' Association of Ontario (RNAO). Developing and sustaining interprofessional health care: optimizing patients/clients, organizational, and system outcomes [Internet]. Toronto (ON): RNAO; 2013. Available from: RNAO.ca/bpg/guidelines/interprofessional-team-work-healthcare (English) RNAO.ca/sites/rnao-ca/files/DevelopingAndSustaining_15_FR_LR_0.pdf (French)	■ Identifies attributes of interprofessional care that will optimize quality outcomes for patients, providers, teams, the organization and the system. ■ Based on the best available evidence. Where evidence was limited, the recommendations were based on the **consensus**[G] of expert opinion.
Residential Hospices Working Group. Strengthening Ontario's end-of-life continuum: advice regarding the role of residential hospices [Internet]. [place unknown]: Hospital Palliative Care Ontario; 2015. Available from: https://www.hpco.ca/wp-content/uploads/Strengthening-Ontarios-End-of-Life-ContinuumFINAL-March-15.pdf	■ Identifies priorities, actions, capacity and planning models to strengthen the end-of-life continuum of care in Ontario, and to optimize the role of residential hospices. ■ Discusses care delivery by interprofessional teams.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Interprofessional Health Collaborative. A national interprofessional competency framework [Internet]. [place unknown]: Canadian Interprofessional Health Collaborative; 2010. Available from: https://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf	■ National interprofessional competency framework.

RESOURCE	DESCRIPTION
Canadian Nurses' Association (CNA). Interprofessional collaboration [Internet]. Ottawa (ON): CNA; c2019. Available from: https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/interproffessional-collaboration_position-statement.pdf?la=en&hash=5695B7264EB8EE6FA1A4B1A73A44A052F0FEA40F (English) https://www.cna-aiic.ca/-/media/cna/page-content/pdf-fr/la-collaboration-interprofessionnelle_enonce-de-position.pdf?la=fr&hash=3EA2FF1F4DB39B01AC38FD5A66B6DB10E6B31C54 (French)	■ Position statements, research syntheses, tools and resources related to interprofessional collaboration.
Canadian Interprofessional Health Collaborative (CIHC) framework. In: McGill: Office of Interprofessional Education [Internet]. Montreal (QC): McGill University; c2019. Available from: https://www.mcgill.ca/ipeoffice/ipe-curriculum/cihc-framework (Website available in English and French)	■ Canadian Interprofessional Health Collaborative framework. ■ Information regarding curriculum, training and preparation of students for interprofessional and collaborative patient-centered care and practice.
ARTICLES	
Hartrick Doane G, Stajduhar K, Causton E, Bidgood D, Cox A. End-of-life care and interprofessional communication: not simply a matter of "more." Health and Interprofessional Practice. 2012;1(3):5.	■ Examines the mechanisms of communication impacting interprofessional team practice and coordinated palliative care on acute medical and long-term care units.
Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. BMJ. 2014 Jun 6;348:g3496.	■ Examines impact of specialist palliative care teams on patients being in hospital in the last two weeks of life, emergency department visits in the last two weeks of life, and dying in hospital.

RECOMMENDATION 1.2:

The expert panel recommends that the interprofessional health team, in collaboration with the person and family, develop an individualized, person-centred plan of care and re-evaluate the plan of care based on the changing status, needs and preferences of the person.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

The evidence on the development of a **plan of care**[G] by the interprofessional health team varied with respect to team composition and health context. However, the literature generally demonstrated that the development of an individualized person-centred plan of care by the interprofessional health team—in collaboration with the person receiving care and their family—may improve transitions in care, coordination of care, access to care, and the experiences of care for persons and families.

Transitions in Care and Coordination of Care

Care planning with an interprofessional health team can promote the provision of holistic care, because the perspectives gained from interprofessional health team discussions may be more comprehensive than independent provider assessments (50). Developing a plan of care with the interprofessional health team, the person receiving care and their family involves **shared decision-making**[G] and ongoing communication. This communication and collaboration improves transitions in care, including both the quality of a person's transition to end-of-life care and the transition from home care to an in-patient hospice setting (51, 55). In one **qualitative research**[G] study, individualized plans of care were discussed with persons and their families during home visits prior to being reviewed at interprofessional health team meetings. Plans of care were subsequently modified based on the changing physical and psychological needs of the person and family. If care could not be provided in the home, and if hospice eligibility was met, the transition to a hospice setting was facilitated (51). In rural environments, care coordination was supported by members of the interprofessional health team, with health providers discussing their unique roles on the team to help ensure that persons with progressive life-limiting illness and their families received appropriate and comprehensive care (45).

Experiences of Care for Persons and their Families, and Access to Care

Active involvement of the person and family in care planning with the interprofessional health team may facilitate positive person and family experiences, and it may increase satisfaction with care (48). For persons with early-stage cancer, for instance, evidence indicates that care planning with the interprofessional health team may improve the person's quality of life and spiritual well-being and reduce psychological distress (53). Furthermore, with regards to access to care, interprofessional care planning may increase the number of referrals to specialized services, including referrals to palliative care, supportive care, chaplaincy, nutrition and social work (53). Care planning with the person, family and interprofessional health team also may allow for discussion and acknowledgement of the person's preference for place of death and improve the person's emotional responses to dying (49, 51). A reduction of pain experienced by the person also may occur (49).

Care planning with the interprofessional health team also may improve the family's experience with care received. For example, caregivers who are part of end-of-life discussions report increased satisfaction with care, and they are more receptive to bereavement visits and experience less distress during those visits (49). When families are included in the care planning process, family caregivers report improvements in their quality of life, a reduction in psychological distress and a reduction in caregiver burden (52).

Interestingly, one study found that caregivers who are *not* part of interprofessional care planning may have greater spiritual well-being than those who *are* part of the care planning. The authors of the study report that this may be due to the intervention being provided with insufficient frequency, and that minimal content related to spiritual well-being was discussed during the intervention (52).

Values and Preferences

Persons value being involved in care planning, and because their family may represent a source of social support, both groups value the opportunity to be involved in decision-making (56).

Health Equity

The expert panel recognizes that some persons receiving palliative care and end-of-life care may have reduced social and financial resources; this may influence individualized care planning and transitions in care (51). The expert panel also acknowledged that access to the resources required for an interprofessional approach to care planning may be limited in certain health-service organizations or geographical locations, which can negatively impact health equity. For example, one study found that when access to specific health providers was limited, functioning of the interprofessional health team and overall care delivery were affected (50).

In another study, providers in rural environments recognized their role in collaborating with one another to advocate for the needs of populations underserved by the health system. While meeting face-to-face with persons with progressive life-limiting illness and their families was valued, providers reported that opportunities and resources were not readily available to them to engage in interprofessional care planning in an effective manner (45).

Expert Panel Justification of Recommendation

There were several benefits identified when the person and their family collaborated with the interprofessional health team in their care planning, and no harms were found. Despite the low certainty of evidence and low confidence in the evidence, the expert panel determined that persons and their families would value improvements in: (a) coordination of care, (b) transitions in care, (c) access to care, and (d) experiences with care. For that reason, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

Implementation considerations from the expert panel:

- Early referrals to interprofessional palliative care teams, along with early conversations between persons with progressive life-limiting illness, families and the interprofessional health team are important in order to discuss preferences, values and plans of care. The importance of early conversations and care planning with the interprofessional health team, person and family is also echoed in the literature (53). If conversations with the person are initiated in the later stages of a person's illness, they may be too unwell to participate in discussions regarding their transitions in care (55).
- Plans of care should be modified in a timely manner based on the changing health status and the needs of the person and family. This will help to support coordination of care, transitions in care and positive person and family experiences.
- Documenting and sharing the plan of care between interprofessional health team members is important. Ongoing and frequent communication (in-person or through written or electronic documentation) between the interprofessional health team and the person and family is a facilitator to achieving the benefits of coordinated and collaborative care planning (47).
- In order to support coordination and continuity in care, interprofessional collaboration should exist both within and between health-service organizations when persons and families transition between settings.

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Biddy R, Griffin C, Johnson N, Larocque G, Messersmith H, Moody L et al. Person-centred care guideline [Internet]. Toronto (ON): Cancer Care Ontario; 2015. Available from: https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/38631	■ Provides recommendations for providing person-centred care in the delivery of adult oncology services in Ontario. ■ Includes recommendations regarding individualized approaches to care and the involvement of family members and caregivers.
Cancer Care Ontario (CCO). Palliative Care Tools [Internet]. Toronto (ON): CCO; 2013. Available from: http://ocp.cancercare.on.ca/cms/One.aspx?portalId=77515&pageId=76967	■ Tools targeted at the generalist provider with the goal of improving the quality of patient care through increased consistency across providers and settings. ■ Includes collaborative care plans for the: stable stage, transitional stage and end-of- life stage.

RESOURCE	DESCRIPTION
Registered Nurses' Association of Ontario (RNAO). Person- and family-centered care [Internet]. Toronto (ON): RNAO; 2015. Available from: RNAO.ca/bpg/guidelines/person-and-family-centred-care (English) RNAO.ca/bpg/language/soins-ax%C3%A9s-sur-les-besoins-de-la-personne-et-de-la-famille (French)	■ Provides recommendations regarding person- and family-centered care. ■ Includes recommendations regarding care planning in partnership with the person receiving care. ■ Based on the best available evidence; where evidence was limited, the recommendations were based on the consensus of expert opinion.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Hospice Palliative Care Association (CHPCA). A model to guide hospice palliative care: based on national principles and norms of practice. Revised and condensed edition [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf	■ National model for hospice palliative care to create a shared vision and a consistent, standardized approach to care delivery, organizational development, education and advocacy across the country. ■ Model to guide person and family care; includes a section regarding care planning.
Quality Palliative Care in Long Term Care Alliance (QPC-LTC). Palliative Performance Scale (PPS) and palliative care conferences [Internet]. [place unknown]: QPC-LTC; 2013. Available from: http://www.palliativealliance.ca/assets/files/Alliance_Reources/Physical_Care/PPS._edited_Jan_242013.pdf	■ Provides information regarding palliative care conferences, which are used to provide information to family members, staff and the resident (if able to attend), and to discuss care planning. ■ The Palliative Performance Scale (PPS) measures functional level and progressive decline of a person receiving palliative care. It also appears to have some prognostic value for persons who have an advanced oncologic disease.

RECOMMENDATION QUESTION #2:

What nurse-led interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life?

Outcomes: Support for spiritual care; support for emotional care; support for existential care; care in alignment with the person's wishes; culturally safe care; place of death

The following recommendations are applicable within the context of an interprofessional health team (see **Recommendations 1.1** and **1.2**).

RECOMMENDATION 2.1:

The expert panel recommends that nurses assess the cultural needs and values of persons and families.

Strength of the recommendation: Strong

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Qualitative evidence indicates that assessing the **cultural needs**[G] and values of persons and families enables nurses to provide culturally safe palliative care and end-of-life care, bridge gaps in communication and gain an inclusive understanding of the person and family (19, 57). In some cases, language barriers can make it difficult to understand a person's cultural beliefs, needs and values; this can potentially lead to gaps in communication, as persons and families are unable to express their needs and wishes and/or health providers have difficulty understanding them (57). **Table 5** provides information from the literature on the components of cultural assessments and on strategies for conducting them.

Values and Preferences

No literature was identified that reported on the values and preferences of persons, their families or their health providers with respect to assessing the cultural needs and values of persons and families.

Health Equity

Incorporating a cultural assessment as part of a comprehensive assessment promotes inclusive care for all populations (19). When language barriers exist, access to high-quality translation services represents an important factor in effectively communicating with persons and families; however, not all health-service organizations have the funding and resources to implement translation services. It is important to note that translation is not interpretation: translation services that can interpret information, promote understanding and meet the individual needs of persons and families are required.

Expert Panel Justification of Recommendation

The expert panel attributed value to conducting cultural assessments so that care plans can be tailored to the person's needs and preferences. Moreover, the expert panel determined that persons would value even small improvements in their care if they received culturally safe care that was in alignment with their wishes. Therefore, despite the fact that there was low confidence in the evidence, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- Organizational policies for health providers are required in order to facilitate culturally safe care in palliative care and end-of-life care (46).
- Nurses should regularly assess their knowledge level and ability to conduct an appropriate cultural assessment prior to doing so in clinical practice, and the expert panel highlights that trust must be established before conversations with persons and families occur. Furthermore, communication is central to culturally safe care, and nurses must avoid making assumptions about persons and families, regardless of their cultural, ethnic or spiritual background (46, 61).
- The expert panel emphasized that culture is unique to each individual, and there are individual differences within the same cultural umbrella.
- While culture is defined broadly, evidence within the systematic review was not found specific to certain population groups. Research is required in these areas. Refer to **Table 10** for research gaps and future implications.

Table 5: Components and Strategies for Cultural Assessments Identified within Research Literature and by the Expert Panel

Components of cultural assessments	Components within the research included: ■ Exploring the person's family context, coping strategies, holistic needs, expression of emotions, meaning of behaviours and all dimensions of pain (57). ■ Within the literature, nurses reported that because a person's experience of suffering is multidimensional, it was valuable to explore their experience from various domains in order for the person to feel truly understood (19). Components identified by the expert panel: ■ Asking persons and families if they have any religious or cultural concerns related to progressive life-limiting illness and death may assist in assessing the cultural needs and values of persons and families. ■ For a subset of the population, culture and spirituality are intertwined; thus, acknowledging both domains during a cultural assessment may be warranted (see **Recommendations 2.2** and **2.6**).

Strategies for conducting cultural assessments	Strategies within the research included: ■ Nurses observed persons and families to learn about care practices and inquired about practices that would typically be conducted at home (57). ■ A cultural assessment may also involve the active involvement of family, including determining the family contact person, exploring factors of personal importance to the family and examining family communication (57). Strategies identified by the expert panel: ■ Cultural assessments should be implemented and completed as part of a holistic approach to care, as outlined in **Figure 2**: Domains of Issues Associated with Illness and Bereavement. Assessment findings should be communicated with members of the interprofessional health team and documented. ■ Nurses should recognize situations wherein persons and families do not wish to partake in cultural assessments. Recognizing and responding to verbal and non-verbal cues regarding the appropriateness of such assessments for the person and their family is integral. ■ The expert panel also recognized that some populations, such as those who are experiencing homelessness or incarceration, may not have family available to provide support, and thus they would have unique support needs with regards to palliative care and end-of-life care.

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Indigenous Relationship and Cultural Safety Courses. In: Cancer Care Ontario [Internet]. Toronto (ON): Cancer Care Ontario; c2019. Available from: https://www.cancercareontario.ca/en/resources-first-nations-inuit-metis/first-nations-inuit-metis-courses	■ Indigenous relationship and **cultural safety**[G] courses.
Culturally Sensitive Care. In: College of Nurses of Ontario [Internet]. Toronto (ON): College of Nurses of Ontario; [reviewed 13 Dec 2018]. Available from: http://www.cno.org/en/learn-about-standards-guidelines/educational-tools/ask-practice/culturally-sensitive-care/ (Website available in English and French)	■ Scenarios for nurses providing culturally sensitive care.
Improving End-of-life Care in First Nations Communities [Internet]. Thunder Bay (ON): Lakehead University; [date unknown]. Available from: http://eolfn.lakeheadu.ca/	■ Information on a project related to improving end-of-life care in First Nations communities.
Palliative Care Toolkit for Indigenous Communities. In: Cancer Care Ontario [Internet]. Toronto (ON): Cancer Care Ontario; [date unknown]. Available from: https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities (Website available in English and French)	■ Palliative care toolkit for Indigenous communities.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Multifaith Federation [Internet]. North York (ON): Canadian Multifaith Federation; [date unknown]. Available from: http://www.omc.ca/	■ Provides services and advocates on spiritual and religious matters for Canadians.

RESOURCE	DESCRIPTION
Canadian Nurses Association (CNA). Promoting cultural competence in nursing [Internet]. Ottawa (ON): CNA; 2010. Available from: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/ps114_cultural_competence_2010_e.pdf?la (English) https://www.cna-aiic.ca/-/media/cna/page-content/pdf-fr/enonce_de_position_encourager_la_competence_culturelle_dans_les_soins_infirmiers.pdf?la=fr&hash=89D7C1B4E1739D3FA949053516A4A165BFECD020 (French)	■ Position statement regarding promoting cultural competence in nursing.
Culturally Connected [Internet]. Vancouver (BC): Culturally Connected; [date unknown]. Available from: https://culturallyconnected.ca/	■ Tools to help health providers establish cultural safety for diverse clients.
Egale Canada Human Rights Trust. Crossing the rainbow bridge: a resource supporting end-of-life planning and care needs of LGBTQI2S adults in Ontario [Internet]. Toronto (ON): Egale Canada Human Rights Trust; 2017. Available from: https://egale.ca/crossing-rainbow-bridge/	■ Resource supporting end-of-life planning care needs of older lesbian, gay, bisexual, transgender, queer or questioning, intersex and two-spirit (LGBTQI2S) adults in Ontario.
Find translated health information [Internet]. Victoria (AU): Health Translations; c2016. Available from: http://healthtranslations.vic.gov.au/	■ Resource to find translated health information.
Framework on palliative care in Canada. In: canada.ca [Internet]. Ottawa (ON): Government of Canada; 2018. Available from: https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p2.3.1 (Website available in English and French)	■ Provides a framework for palliative care in Canada. ■ Includes a sub-section on Indigenous persons and valuing the diversity of Canada and its peoples.
Living My Culture.ca [Internet]. [place unknown]: Canadian Virtual Hospice; c2016. Available from: http://livingmyculture.ca/culture/	■ People from a variety of cultures share stories and wisdom about living with serious illness, end of life and grief.

RESOURCE	DESCRIPTION
Spiritual Health [Internet]. [place unknown]: Canadian Virtual Hospice; c2003–2017. Available from: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Spiritual+Health.aspx (Website available in English and French)	■ Includes information regarding spiritual care and life-limiting illness, finding a spiritual companion, finding meaning and purpose during a health crisis, rituals for persons and families, rituals to comfort families and sharing your story.
Tools for Practice [Internet]. [place unknown]: Canadian Virtual Hospice; c2003–2017. Available from: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/Tools+for+Practice/Culture.aspx#id_d162ec47e21d5a15ef45c0185564dc97 (Available in English and French)	■ Information and support on palliative care and end-of-life care, loss and grief, including a sub-section focused on culture.
Training Materials [Internet]. [place unknown]: Multicultural Mental Health Resource Centre; c2019. Available from: http://www.multiculturalmentalhealth.ca/training/cultural-competence/cultural-competence-tools-and-guidelines/ (Website available in English and French)	■ Contains resources on cultural competency compiled from different organizations.

RECOMMENDATION 2.2:

The expert panel recommends that nurses perform ongoing assessments of persons and families for the following:

- values, beliefs, expectations and preferences about progressive life-limiting illness and death; and
- preferred place of death.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Very low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

The research evidence demonstrates the importance of nurses discussing with persons and their families their values, beliefs, expectations and preferences about their life-limiting illness, death and preferred place of death. Doing so will support future care planning and the person's ability to experience a death in alignment with their wishes.

Values, Beliefs, Expectations and Preferences about Progressive Life-limiting Illness and Death

Qualitative evidence demonstrates that when nurses and other health providers discuss care preferences with persons and their families, it may promote the establishment of a trusting rapport between the nurse and patient, encourage open communication and allow them to identify areas in which coordination of care is required (62). Engaging and supporting the person to be involved actively in the decision-making process also can have psychological benefits for the person, including providing them with a sense of control and self-determination (62). In a study that evaluated a nurse practitioner-directed intervention that focused on the effect of exploring the values, beliefs, preferences and expectations of persons, the emotional well-being of persons at the end of life was found to improve; however, the intervention was not found to have an impact on their spiritual well-being (63).

Preferred Place of Death

Examining a person's preferred place of death can promote a holistic approach to care (e.g., emotional and psychological) that extends beyond physical symptom management. Nurses within a qualitative study acknowledged that a person's preferred place of death may change over time or may not be feasible; however, initiating the conversation with the person is viewed as an important first step in assessing whether the person's request is attainable (62). Potential issues may arise if a person's care preferences are not feasible; this can result in negative emotional outcomes for persons, families and health providers (62).

Values and Preferences

Changes in care preferences are occasionally associated with alterations in a person's health condition, but the experience and direction of these changes are unique to the person receiving the care (67). Potential shifts in a person's care preferences indicate a need for ongoing assessment of their care preferences as end of life approaches (68).

One study noted that discussing the topic of a person's preferred place of death too early, particularly if the person is not yet aware of their proximity to death, may be perceived as unsupportive and uncaring (62). When persons do not wish to engage in discussion on topics such as preferred place of death, the topic can be revisited at a more appropriate time, depending on the person's needs and wishes (62). The expert panel acknowledged that the interprofessional health team should explore the person's understanding of their illness early in the palliative care trajectory, before conversations are initiated regarding a person's preferred place of death.

Health Equity

A person's decision with regards to preferred place of death is multi-faceted. The expert panel highlights that a person's choice for preferred place of death may be influenced by access to supportive care providers, living in rural or remote areas, complications of illness, access to supplies and medication, and caregiver **burnout**[G]. These factors can ultimately impact health equity.

Unfortunately, although the evidence shows that most people prefer to die at home, over 60 per cent of Canadians continue to die in hospitals, and only 15 per cent receive palliative home care services in the last month of life (16, 64, 65).

Expert Panel Justification of Recommendation

Despite the very low certainty of the evidence of effects and the low confidence in the evidence, the expert panel determined that the benefits outweigh the harms when it comes to assessing the preferred place of death and the values, beliefs, expectations and preferences of a person and their family. The expert panel also believes that persons would value improvements in spiritual, emotional, existential and culturally safe care, and that they would appreciate receiving care in alignment with their wishes. For that reason, the panel determined the strength of the recommendation to be strong.

Practice Notes

- Persons with progressive life-limiting illness experience changes regarding expectations for their life and future as they come to terms with the nature of their illness (66). The expert panel emphasized that the conversation about preferred place of death is dynamic, and that assessment must continuously occur as the person's condition and needs change (i.e., it is not a static situation). Ongoing assessments reflect that status and needs of the person, and thus may include re-assessments as well as new assessments.
- The expert panel also highlights the importance of considering the family and **substitute decision-makers**[G] in discussions regarding preferred place of death.
- The expert panel emphasized that communicating assessments to the interprofessional health team is important. It is also important to document the person's preferences in their plan of care and to re-assess as changes occur; this will allow attention to be paid to the person's care expectations throughout the trajectory of their illness (62).
- Refer to **Appendix M** for resources related to advance care planning and goals of care.

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Health Quality Ontario (HQO). Palliative care: care for adults with a progressive, life-limiting illness [Internet]. Toronto (ON): Queen's Printer for Ontario; 2018. Available from: https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-en.pdf (English) https://www.hqontario.ca/portals/0/documents/evidence/quality-standards/qs-palliative-care-clinical-guide-fr.pdf (French)	■ Quality standard addressing palliative care for people who are living with a serious life-limiting illness, and for their family and caregivers. ■ Includes discussion of goals of care, **setting of care**[G] and place of death.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Ariadne Labs: A Joint Center For Health Systems Innovation. Serious illness conversation guide [Internet]. [place unknown]: Ariadne Labs; 2018. Available from: http://www.bccancer.bc.ca/new-patients-site/Documents/SeriousIllnessConversationGuideCard.pdf	■ Serious illness conversation guide, including conversation flow and patient-tested language.
Canadian Virtual Hospice. Decision making in palliative care: a guide to approaching care choices [Internet]. [place unknown]: Canadian Virtual Hospice; [date unknown]. Available from: http://www.virtualhospice.ca/Assets/decisionmakinginpc-harlos_20081127165936.pdf	■ Guide to approaching care choices.
Is Palliative Care Right for You? In: Get Palliative Care [Internet]. [place unknown]: Center to Advance Palliative Care; c2019. Available from: https://getpalliativecare.org/rightforyou/	■ Questions to determine whether palliative care might be right for a person or someone close to them.

RECOMMENDATION 2.3:

The expert panel suggests that as part of a holistic assessment, nurses assess the spiritual, emotional and existential needs of persons and families, including:

- concerns about end of life; and
- presence of spiritual, emotional and existential distress.

Strength of the recommendation: Conditional

Certainty of the evidence of effects: Very low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Assessing the spiritual, emotional and existential needs of persons and families represents one important aspect of person- and family-centered holistic care. Refer to **Table 6** (below) for strategies identified within the literature to assess the spiritual, emotional and existential needs of the person and their family.

Assessment of Spiritual, Emotional and Existential Needs

When assessing for spiritual, emotional and existential needs, health providers asked questions pertaining to a range of topics, including the following:

- concerns, hopes, dreams and wishes;
- feelings of peace;
- impact of illness on family;
- whether the person is part of a spiritual or religious community; and
- meaning behind feelings of sadness, guilt or defeat (69).

Evidence suggests that persons and families may respond positively to nurse-led spiritual assessments. In a study by Taylor & Brander (2013), persons were given a 21-item spiritual assessment questionnaire to ascertain their comfort level when being asked questions pertaining to spirituality. Approximately 25 per cent of the respondents "liked to be asked", approximately 50 per cent were "okay" with being asked, and approximately 25 per cent "did not want to be asked" questions pertaining to spirituality (70). Persons were also receptive to questions about support systems, because it allowed them to reflect on what was helpful to them during difficult times in the past, and it prompted them to recall positive aspects of their lives (70). Moreover, when nurses supported persons to share their feelings, persons were able to gain trust in the nursing care they received (71). However, nurses also reported instances in which the family was not psychologically prepared to discuss loss; this in turn caused distress for the person, their family and the nurse (69).

Presence of Spiritual, Emotional and Existential Distress

In a qualitative study, hospice nurses emphasized the importance of identifying spiritual distress in persons with life-limiting progressive illness, and they recognized this as an experience unique to each individual (72). Moreover, these domains can be heavily intertwined with a person's physical health, such that nurses in one study assessed for existential and spiritual distress during their assessment of the person's total pain experience (73). When hospice nurses recognize and provide the appropriate care to persons in spiritual distress, nurse–person relationships may be positively impacted. For example, when persons were actively in distress, hospice nurses used open-ended questions to explore the person's feelings and provide them with the opportunity to express their emotions, if they desired. Thus, hospice nurses who engaged in conversation with the person in a professional manner allowed persons to express their emotions, obtain needed support and alleviate emotional suffering (74).

Values and Preferences

Variability in preferences regarding spiritual, emotional and existential assessments was found in the literature. In one study, some persons did not wish to be asked about their involvement in a religious community, and they felt that it was inappropriate for nurses to ask questions about their spiritual beliefs (70). Some persons and families stated that they preferred their spiritual assessment to be conducted first by spiritual care experts, followed by counselors and then nurses (70).

Health Equity

The expert panel acknowledged that health equity may vary due to issues related to resources and staffing, in addition to provider education and training in how to conduct spiritual, emotional and existential assessments for persons with a life-limiting progressive illness.

Expert Panel Justification of Recommendation

There were both benefits and harms identified for completing spiritual, emotional and existential assessments. The expert panel noted that although conducting these assessments is valuable, not all individuals may wish to answer questions or partake in assessments of this nature. Responding to cues (verbal and non-verbal) and recognizing the appropriateness of such assessments for the person and their family is integral to quality holistic care. Given the very low certainty of the evidence of effects, the low confidence in the evidence, and the variability in how persons value these assessments, the expert panel determined the strength of the recommendation to be conditional.

Practice Notes

- The expert panel emphasized that nurses should reflect on their knowledge level, comfort and ability to conduct appropriate spiritual, emotional and existential assessments prior to doing so, because when such assessments are done incorrectly—or if the nurse is not prepared to deal with the outcomes of the assessment—they can be harmful to persons and their families.
- Organizations can support health providers to engage in these assessments by providing appropriate training so that they can gain an understanding of the person and more appropriately assess and explore their needs (75).
- Assessments should be communicated to the interprofessional health team and documented. Moreover, the expert panel highlighted the importance of nurses recognizing when the complexity of the needs of the person and their family exceeds their knowledge, training and scope of practice. In these instances, interprofessional approaches may be necessary to meet the needs of persons and families, and nurses should seek the involvement of appropriate interprofessional health team members in a timely manner (76). Interprofessional health team support has been demonstrated to assist in addressing spiritual needs, particularly when health providers are not comfortable addressing spiritual care needs when it is beyond their knowledge or skill (76).

- The expert panel identified that home care nurses must know the supports available within the community in order to connect persons and families to appropriate resources.
- The expert panel emphasizes that the physical and psychosocial domains of health are interrelated. Thus, when physical incapacity is an issue, the person may experience emotional distress related to their loss of independence and functional ability. Similarly, while pain control represents a central aspect of palliative care and end-of-life care, pain is a multidimensional concept: the "total pain" a person experiences is influenced by physical, psychological, social and spiritual factors (77). All of these factors are interrelated and must be considered in unison to gain an accurate understanding of the person (77).
- Refer to **Appendix G** for a list of assessment tools that explore different domains of health and illness as part of a holistic approach to care.

Table 6: Strategies Identified within the Research Literature to Assess the Spiritual, Emotional and Existential Needs of the Person and Their Family

Strategies to assess spiritual, emotional and existential needs	■ Being genuine and present, listening, and spending quality time with persons and families (72). ■ Once trust and rapport are established, utilizing non-intrusive ways to explore the spiritual or existential beliefs of persons in their care (73). ■ Recognizing the importance of reading body language and non-verbal cues as part of the assessment, and the importance of being mindful of their own non-verbal behaviour during the process (69). ■ Assessments also involve the needs of the family, including coping, communication and family dynamics (73). ■ An assessment of a person's spiritual, emotional and existential preferences needs to be initiated early in a person's illness trajectory. This provides the interprofessional health team with the means to ensure that the person's preferences are honoured at the time of death (78).
Areas explored through assessment questions	■ Feelings of peace. ■ The impact of illness on family. ■ Whether the person is part of a spiritual or religious community. ■ The meaning behind feelings of sadness, guilt or defeat. ■ Problems, concerns, hopes, dreams and wishes (69).
Signs of spiritual distress	■ Some signs of spiritual distress for a person at the end of life, as identified within the research, include the following: □ questioning the meaning of life; □ changes in behaviour, such as withdrawing or distancing oneself from others; and □ physical symptoms, such as pain (72).

Supporting Resources

RESOURCE	DESCRIPTION
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Hospice Palliative Care Association (CHPCA). How spiritual care practitioners provide care in Canadian hospice palliative care settings: recommended advanced practice guidelines and commentary [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.chpca.net/media/319456/chpca_spiritual_advisors_--recommended_practice_guidelines_--_31october_2013.pdf	■ Recommended advanced practice guidelines and commentary regarding how spiritual care practitioners provide care in Canadian hospice palliative care settings.
Welcome to Spiritual Care [Internet]. In: Canadian Association for Spiritual Care. Ottawa (ON): Canadian Association for Spiritual Care; [date unknown]. Available from: http://www.spiritualcare.ca	■ Education, certification and resources for spiritual care providers.
ARTICLES	
Balboni TA, Fitchett G, Handzo GF, Johnson KS, Koenig HG, Pargament KI et al. State of the science of spirituality and palliative care research part II: screening, assessment, and interventions. J Pain Symptom Manage. 2017 Sep;54(3):441-53.	■ Report addressing the current landscape of research regarding spirituality and palliative care. ■ Identifies next steps to advance the field.

RECOMMENDATION 2.4:

The expert panel recommends that nurses address the person's and family's palliative care and end-of-life care expectations.

Strength of the recommendation: Strong

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Generally, evidence from qualitative literature identifies that addressing palliative care and end-of-life care expectations with persons and their families may promote supportive care and care that is delivered in harmony with the person's wishes (62, 69, 79). To address expectations in a supportive way, nurses—in collaboration with the interprofessional health team—need to ensure that persons have realistic expectations about the care that can be provided, the type of assistance that can be given and the amount of time that can be dedicated in order to prevent feelings of disappointment (62, 69). Addressing expectations also involved preparing the person for anticipated care and exploring the person's and family's current understanding of palliative care (79).

Harmony between persons and their families on palliative care and end-of-life care issues may improve quality care and facilitate a comfortable death for the person (79). Moreover, nurses provided continuous support to family members by engaging them throughout the care process and offering appropriate support in the face of escalating family stress, particularly if they were having difficulties with coping (79). When nurses were not able to manage expectations, the nursing relationship was compromised, nurses were not able to provide quality care and the person may not have experienced a comfortable death (79).

Values and Preferences

Persons value supportive discussions, opportunities to discuss questions they may have and receiving information from health providers in order to obtain information on their condition and treatment possibilities (66).

Health Equity

The expert panel acknowledged that health equity may vary due to issues related to resources and staffing, and differences in provider education and training in how to assess expectations of palliative care and end-of-life care.

Recognition of how social determinants of health impact access to and provision of palliative care and end-of-life care must be considered in order to support access to care for those who are structurally vulnerable.

Expert Panel Justification of Recommendation

Several benefits were identified as a result of addressing the end-of-life care expectations of the person and their family. Despite low confidence in the evidence, the expert panel attributed value to addressing the expectations of the person and their family. For that reason, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- Nurses should assess the readiness of persons to discuss their expectations for palliative care and end-of-life care and their understanding of their illness. The expert panel emphasized that conversations should occur at an appropriate time (i.e., when persons are ready), and that it should be early in the care process. When nurses and the interprofessional health team facilitate early conversations, it promotes empowerment and provides an opportunity for the person to make decisions while mentally capable of doing so (i.e., as opposed to decisions being made by a substitute decision-maker if conversations are initiated when the person is no longer mentally capable).
- The expert panel emphasized that past experiences with death and past coping strategies may impact palliative care and end-of-life care expectations. When nurses and the interprofessional health team engage in dialogue with the person and family on their care expectations, the person's values and preferences can be thoughtfully reflected in the care plan.
- Communication with persons needs to be flexible to meet their individual needs.
- It is important to note that consent for treatment(s) within the plan of care is given by the person receiving the care or, if the person is incapable, by their substitute decision-maker in accordance with the person's goals and wishes.
- Strategies identified in the literature that nurses can use to achieve agreement between persons and their families include the following:
  - providing ongoing support to ensure that families remain engaged throughout the care process;
  - accommodating individuality and each family's unique ways of caring;
  - preparing families for forthcoming care; and
  - being responsive to individual perspectives and remaining flexible regarding family practices in order to facilitate positive engagement with persons and families (79).

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Caregiver tips for coping with advancing illnesses. In: Elizz.com [Internet]. [place unknown]: Saint Elizabeth Health Care; 16 Feb 2017. Available from: https://elizz.com/caregiver-resources/planning/coping-with-advancing-illness	■ Includes caregiver tips for coping with advancing illnesses.
Speak Up Ontario [Internet]. Toronto (ON): Speak Up Ontario; c2019. Available from: https://www.speakupontario.ca/	■ Resources to improve awareness of health care consent and advance care planning in Ontario. ■ Ontario has unique requirements with respect to health care consent and advance care planning. These resources and tools are specific to the Ontario legal context.

RESOURCE	DESCRIPTION
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Graham C. Everything nobody tells you about cancer treatment and your sex life: from A to Za Za Zoom [Internet]. [place unknown]: City of Hope Pain and Palliative Care Resource Center; 2014. Available from: http://prc.coh.org/A-Z%20Booklet%209-14.pdf	■ Resource regarding the impact of cancer treatment on a person's sex life.
Macmillan K, Peden J, Hopkinson J, Hycha D. A caregivers guide: a handbook about end-of-life care [Internet]. Ottawa (ON): Military and Hospitaller Order of St. Lazarus of Jerusalem; 2004. Co-published by the Canadian Hospice Palliative Care Association. Available from: https://hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf	■ Assists family caregivers by complementing the guidance and assistance they receive from palliative care and home-care professionals.
The ABCDs of dignity in care. In: Dignity in Care [Internet]. [place unknown]. Dignity in Care; c2016. Available from: http://www.dignityincare.ca/en/the-abcds-of-dignity-in-care.html (Available in English and French)	■ Guide for putting principles of dignity in care into action.
Toolkit. In: Dignity in Care [Internet]. [place unknown]. Dignity in Care; c2016. Available from: http://www.dignityincare.ca/en/toolkit.html (Available in English and French)	■ Practical tools to support those working in health settings as they address the emotional needs of people.
BOOKS	
Cortes-Miller K. Talking about death won't kill you: the essential guide to end-of-life conversations. Toronto (ON): ECW Press; 2018.	■ Guidance regarding end-of-life conversations.

RECOMMENDATION 2.5:

The expert panel suggests that nurses provide opportunities for life reflection to persons and families.

Strength of the recommendation: Conditional

Certainty of the evidence of effects: Low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Various strategies to enable persons to engage in reflection were explored in the research, including both structured and unstructured approaches. For the purposes of this BPG, "structured approaches" are organized or formal interventions with a specific set of components, while "unstructured approaches" may involve more flexible, natural and spontaneous conversations to explore life reflection. Due to the limited research on structured life reflection interventions, a specific intervention program cannot be recommended at this time (80).

In general, life reflection may support a person-centred approach to care by acknowledging individuality, spirituality, fear and distress in order for persons to find meaning and acceptance and to alleviate their spiritual distress (69, 72, 78, 80). Regardless of the type of strategy used for life reflection, nurses can provide opportunities for reflection to persons living with progressive life-limiting illness and their families.

Unstructured Reflection

In qualitative studies, nurses reported that life reflection—if desired by persons with progressive life-limiting illness—allowed persons to experience a more peaceful death in comparison to those who did not wish to reflect and share (73). Providing opportunities for reflection allowed persons to (a) work through fear and regret, (b) reduce their suffering and (c) find meaning in their lives. In one study, when persons demonstrated fear about death, nurses acknowledged their feelings which eased the person's distress and allowed them to accept what was happening (72). Refer to the Practice Notes section for this recommendation (found below) for strategies identified within the literature that health providers used to engage in reflection conversations.

Structured Reflection

A structured approach to life reflection was generally found to improve spiritual well-being in persons at the end of life, and to demonstrate improvement with regards to existential distress scores and quality of life (81, 82). One study had a high attrition rate due to death, deterioration of condition or refusal to participate in the intervention (82). In another study, some persons found the questions asked as part of the intervention to be upsetting because it emphasized the limited time they had left to live (81). See **Table 7** for more information about the two structured interventions evaluated: Outlook and The Meaning of Life Intervention.

Values and Preferences

Persons reported that the structured intervention brought meaning to their lives; however, some found the questions asked as part of the intervention to be difficult to answer or not relevant to their stage of life (81).

In a 2014 study by Keall et al., nurses reported that persons often wanted to share their story because it humanized them and allowed them to share their wisdom and legacy. Nurses viewed structured intervention positively because it provided a framework for care and supported therapeutic relationships. Nurses also reported that a structured intervention contributed to the holistic care of persons, and that it helped persons identify value in their lives (83).

Health Equity

The expert panel acknowledged that not all health-service organizations have adequate resources (e.g., staff, volunteers, time and training) to support health providers to engage in conversations about life experiences.

Expert Panel Justification of Recommendation

There were both benefits and harms identified for providing opportunities for life reflection. The expert panel felt that the benefits outweighed the harms with regards to the identified outcomes for most people; however, they emphasized that life reflection may not be appropriate for everyone. For some persons, life reflection may be detrimental (e.g., distressing or traumatizing) for their psychological and emotional well-being, especially if they do not wish to engage in the life reflection process or do not find meaning in it. Given the low certainty of evidence of effects, the low confidence in the evidence, and the variability in how persons value opportunities to reflect on their lives, the expert panel determined the strength of the recommendation to be conditional.

Practice Notes

- The expert panel emphasized that in order to provide effective support to persons with progressive life-limiting illness and their families—and to provide opportunities for reflection—nurses and other health providers must first be provided with training to enhance their practice with the knowledge and skills needed to approach life reflection conversations. This includes trauma-informed approaches and recognizing when such conversations may not be appropriate. See **Appendix B** for a resource related to trauma-informed approaches.
- A person- and family-centred approach to life reflection includes providing flexibility, both in the timing of the dialogue and in the number of sessions offered (81). For instance, life reflection should not be introduced immediately after the diagnosis of a progressive life-limiting illness because time is required for a person to process the information and adapt. The authors of one review study also suggest that life reflection programs remain brief in duration due to the shortened life expectancy of persons at the end of life (80).
- Strategies identified within the literature that were used by health providers to engage in life reflection conversations with persons with progressive life-limiting illness included the following:
  - spending time with persons in a non-judgemental manner;
  - establishing rapport and trust with the person (72, 78);
  - acknowledging the individuality of the person;
  - demonstrating compassion;
  - communicating with persons with full attention;
  - facilitating a safe environment (72);
  - sharing in silence with the person in order to demonstrate openness and availability for support (73);
  - providing persons with opportunities to discuss fears, explore hopes and dreams, remember past experiences and reflect on meaning in life (78);

- listening actively in an uninterrupted, open and respectful manner when the person is ready to reflect and speak about their experiences (69); and
- supporting the person without trying to change their circumstances (69).

- Challenges for health providers, such as finding sufficient time to engage in meaningful dialogue with persons and their families, may ultimately lead to the inability to meet a person's needs, creating moral distress and ethical dilemmas for the health provider (73, 84).

Refer to **Table 7** for details on the structured interventions within the research.

Table 7: Descriptions of Structured Interventions

INTERVENTION	FOCUS	COMPONENTS
Outlook (81)	Preparation for end of life and life completion	■ Administered by nurse or social worker. ■ Three sessions over three weeks, with each session of 45–60 minutes. ■ Questions structured around three major themes, with some sample questions below: 1. Life story: □ Tell me about your life. □ What are cherished times? □ What are you most proud of? 2. Regrets and forgiveness: □ If you were to do things again, what would you do differently? □ Are there things or times you regret? □ Is there anyone to whom you would like to offer forgiveness? 3. Heritage and legacy: □ What are your most valuable lessons learned? □ What would you like to share with future generations? □ If you could choose one thing to pass on as your legacy, what would that be?

INTERVENTION	FOCUS	COMPONENTS
Meaning of life (82)	Creation of a legacy product	■ Administered by nurse researcher for persons with cancer, but authors suggest it can be carried out by any member of the interprofessional health team, as minimal training is required. ■ Two in-person sessions over two or three days. ■ Session 1 is a recorded semi-structured interview. Questions include: □ What do you think about your life? □ How have you faced adversity in your life? □ What do you do to love yourself and others? □ What brings you joy? □ What do you appreciate in your life? ■ In between Sessions 1 and 2, the facilitator listens to the recording and extracts information into themes. ■ Session 2 involves reviewing the summary of the interview with the person.

Supporting Resources

RESOURCE	DESCRIPTION
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Bilou S. Legacy work in palliative care: experiences on the tertiary palliative care unit [Internet]. Edmonton (AB): Edmonton Zone Palliative Care Program; 2013. Available from: http://www.palliative.org/NewPC/_pdfs/education/2013%20conference%20materials/Legacy%20Work%20in%20Palliative%20Care%20Best.pdf	■ Provides information on legacy work in palliative care.
Families First presents Have the Talk of a Lifetime: Conversation Cards. In: Families First [Internet]. Ontario (CA): Families First; [date unknown]. Available from: https://www.familiesfirst.ca/talk-of-a-lifetime	■ Initiative encouraging family and friends to share and learn about each other. ■ Focused on sharing memories, telling stories and making every event as personal and meaningful as possible.

RESOURCE	DESCRIPTION
Legacy Activities. In: Hospice of Waterloo Region [Internet]. Waterloo (ON): Hospice of Waterloo Region; [date unknown]. Available from: http://www.hospicewaterloo.ca/resources/legacy-activities/	■ Legacy activities are opportunities for families to share moments together when someone in the family has an advanced illness.
The ABCDs of dignity in care. In: Dignity in Care [Internet]. [place unknown]. Dignity in Care; c2016. Available from: http://www.dignityincare.ca/en/the-abcds-of-dignity-in-care.html (Website available in English and French)	■ Guide for putting principles of dignity in care into action.
Welcome to Spiritual Care [Internet]. Ottawa (ON): Canadian Association for Spiritual Care; [date unknown]. Available from: http://www.spiritualcare.ca	■ Education, certification and resources for spiritual care providers.
BOOKS AND ARTICLES	
Chochinov HM. Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. BMJ. 2007 Jul;335(7612):184-7.	■ Article focused on dignity-conserving care.
Chochinov H. Dignity therapy: final words for final days. Oxford (UK): Oxford University Press; 2011.	■ Provides information on dignity therapy, which addresses many of the psychological, existential and spiritual challenges faced by patients with progressive life-limiting illness and their families.

RECOMMENDATION 2.6:

The expert panel recommends that nurses facilitate access to resources, space and services needed by persons and families for cultural, spiritual and/or religious practices.

Strength of the recommendation: Strong

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Qualitative evidence demonstrates that in order to promote culturally safe care, it is important that nurses facilitate access to the resources, physical space and services needed by persons with progressive life-limiting illness and their families for cultural, spiritual and/or religious practices. By advocating for access to resources, space and services, nurses may be able to recognize potential unmet needs of persons and support persons and families to engage in practices and/or events of personal significance (19).

Facilitating access to space (e.g., by providing opportunities for family to visit outside of visiting hours) allowed persons to spend quality time with loved ones and engage in end-of-life rituals (85). Based on the needs and preferences of the person, nurses also provided referrals to other health providers—such as spiritual care specialists, chaplains, counselors or spiritual leaders—in order to support access to resources and services required for spiritual and/or religious practices (72). One study outlined potential benefits of interpretation services for persons and families experiencing language barriers, including supporting clear communication, gaining a true understanding of the person and family, and promoting continuity of care (57).

Values and Preferences

The evidence highlights the varying preferences and needs of persons with progressive life-limiting illness. Some persons and family caregivers receiving end-of-life care strongly value spiritual care, believing that addressing spiritual and existential concerns are significant aspects of care (86). Engaging in personal practices—such as meditation, prayer, private rituals, discussion of spiritual topics, readings and other spiritual activities—can be significant aspects of their end-of-life care experience (86). Additionally, some persons and families value spiritual care resources, such as books, journals or multimedia (87).

Health Equity

Including families in care and providing persons and their families with translation services, connecting them with traditional healers and making organizational accommodations for cultural or spiritual practices all have the potential to reduce health inequities among populations (20).

With respect to access to spiritual services, hospice nurses in one study reported that after-hours access to specialist health providers—such as spiritual care providers, chaplains and counselors—was a challenge within their organization. Specialist health providers were not readily available on weekends or at night, which was when persons often were experiencing the most distress (72). It was recognized that spiritual care services should have the same after-hours availability as other health services, emphasizing the importance of spiritual care as part of a holistic approach to end-of-life care (72).

Expert Panel Justification of Recommendation

Facilitating access to the resources, spaces and services based on the needs of persons and families was found to be beneficial. Despite the low confidence in evidence, the expert panel determined that persons would value having the opportunity to engage in their cultural, spiritual and/or religious practices. For that reason, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- The expert panel emphasized the necessity for nurses to have the appropriate education, knowledge and skills to engage in cultural, spiritual and/or religious conversations with persons with progressive life-limiting illness and their families.
- Nurses must acknowledge their comfort level prior to engaging in discussions of this nature. Within the literature, some nurses recognized their own limitations and reported mixed feelings with regards to discussing spiritual or religious issues with persons because of their own personal life experiences, beliefs and feelings of insecurity (73, 78). In these situations, however, nurses did facilitate spiritual support for persons by making the appropriate referrals to a chaplain or other spiritual leader (73).
- Other services that may benefit the person and family include: psychological services, counselling, and grief and bereavement support. See **Appendix M** for resources related to grief and bereavement.
- Within the literature, celebrating events of personal significance for persons and their families was recognized as the last opportunity to commemorate certain milestones; in these cases, however, nurses completed preparations for the celebrations outside of working hours and during their personal time (19). Health-service organizations need to allocate resources and time for nurses to accomplish holistic person- and family-centered care, such as preparing for events of personal significance, within working hours.
- Health-service organizations need to provide the adequate resources and space for persons and families to engage in meaningful personal practices.
- Strategies outlined in the literature that were used by nurses to support persons to engage in practices of personal importance include the following:
  - Negotiating with management to allow family members to visit outside of visiting hours in organizations where visiting hours are restricted (85).
  - Ensuring that persons and families had adequate time and space to engage in end-of-life rituals and prayers (85).
  - Providing referrals to other health providers such as spiritual care specialists, chaplains, counselors or spiritual leaders (72). These referrals are based on the needs and preferences of the person and whether they wish to speak to someone about their concerns or issues (69, 78). The referral process requires nurses to be aware of when a referral is indicated and to whom the referral should be directed; this will help to ensure that persons have appropriate access to services (69).
  - Facilitating access to interpretation services for persons and families experiencing language barriers (57).
  - Working collaboratively with families and supporting them in their role as caregivers. Additionally, identifying networks in the community to provide support to the person and their family (88).

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Overview. In: 211 Ontario [Internet]. Ontario (CA): 211 Ontario; [date unknown]. Available from: https://211ontario.ca/about-211-ontario/overview/ (Website available in English and French)	■ Helpline and website that provides information on (and referrals to) Ontario's community, social, health-related and government services.
Palliative Care Toolkit for Indigenous Communities [Internet]. Toronto (ON): Cancer Care Ontario; [date unknown]. Available from: https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities (Website available in English and French)	■ Palliative care toolkit for Indigenous communities.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Nurses Association (CNA). Promoting cultural competence in nursing [Internet]. Ottawa (ON): CNA; 2010. Available from: https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/ps114_cultural_competence_2010_e.pdf?la (English) https://www.cna-aiic.ca/-/media/cna/page-content/pdf-fr/enonce_de_position_encourager_la_competence_culturelle_dans_les_soins_infirmiers.pdf?la=fr&hash=89D7C1B4E1739D3FA949053516A4A165BFECD020 (French)	■ Position statement on promoting cultural competence in nursing.
Living My Culture.ca [Internet]. [place unknown]: Canadian Virtual Hospice; c2016. Available from: http://livingmyculture.ca/culture/	■ Stories from people of different cultural backgrounds about living with serious illness, the end of life and grief.

RESOURCE	DESCRIPTION
Spiritual Health. In: Canadian Virtual Hospice [Internet]. [place unknown]: Canadian Virtual Hospice; c2003–2017. Available from: http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Spiritual+Health.aspx (Website available in English and French)	■ Includes information regarding spiritual care and life-limiting illness, finding a spiritual companion, finding meaning and purpose during a health crisis, rituals for persons and families, rituals to comfort families and sharing your story.
Find translated health information. In: Health Translations [Internet]. Victoria (AU): Health Translations; 2016. Available from: http://healthtranslations.vic.gov.au/	■ Website with translated health information.
Training Materials. In: Multicultural Mental Health Resource Centre. Montreal (QC): Multicultural Mental Health Resource Centre; c2019. Available from: http://www.multiculturalmentalhealth.ca/training/cultural-competence/cultural-competence-tools-and-guidelines/ (Website available in English and French)	■ Training materials for providing culturally safe care.
National Aboriginal Health Organization (NAHO). Cultural competency and safety: a guide for health care administrators, providers and educators [Internet]. Ottawa (ON): NAHO; 2008. Available from: https://en.unesco.org/interculturaldialogue/resources/249	■ Provides background on the origins of cultural competency and cultural safety. ■ Explains the need for culturally competent and safe care, identifies the stakeholders in this process and outlines ways to evaluate health programs and policies.

RECOMMENDATION 2.7:

The expert panel recommends that for persons who prefer to die at home, health-service organizations implement high-quality home and community care, which includes:

- access to after-hours services;
- care coordination; and
- support provided by an interprofessional health team.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Low

Discussion of Evidence:

Benefits and Harms

The majority of research on preferred place of death was conducted at the community and organizational level, focusing on service availability, team composition and environment of care. Overall, the research suggests that high-quality home and community care—which includes access to after-hours services, care coordination and support provided by an interprofessional health team—may enable persons to die at home when that is their preferred place of death. Within this BPG, home is defined by the person receiving care, and it may refer to a physical house or other dwelling, such as long-term care, hospice or other community setting.

Access to After-hours Services

Access to in-person and telephone-based after-hours services may support home deaths for persons with progressive life-limiting illness. The evidence suggests that persons who died at home were more likely to use an after-hours telephone service compared to persons admitted to a care facility (89). As part of a multi-component intervention, an after-hours telephone line was provided to persons and their families. Although it is difficult to confirm if it was the after-hours telephone line or another component of the multi-component intervention that led to the results, the authors found that persons who received the intervention were less likely to die in hospital or have an emergency department admission or visit (90).

In another study, it was found that 77 per cent of persons who received in-person home care and emotional support (available after hours for both day and night shifts) died at home, whereas only 35 per cent died at home when they did not use the service. Persons who received the service and who were cared for at home at the end of life also had lower hospital use, although there may have been increased demands placed on the community services used, such as nursing care, primary care and social care (91).

Care Coordination

Care coordination also may help persons with progressive life-limiting illness to die at home. In one study, a multi-component program that included two end-of-life coordination centres for community referrals as part of the intervention found that persons who used the program were less likely to die in hospital. The authors of the study report that coordination centres for community referrals appear to have the greatest impact on place of death (90).

Relational coordination[G] may also increase the likelihood for persons with progressive life-limiting illness to die at home. When nurse managers engage in high-quality and timely communication with other health providers about a person's preferred place of death, it may result in well-coordinated and individualized care that meets the person's needs (92).

Support Provided by an Interprofessional Health Team

The evidence suggests that home visits by nurses in collaboration with primary physicians and increased duration of nursing services per home visit may be associated with greater frequency of deaths at home and may promote the development of caring relationships between providers, persons and their families (93). When care was provided by a specialist palliative home care team comprised of nurses and physicians, the overall rate of home deaths was 56.6 per cent. Of those who died at home, 62.6 per cent were cared for by palliative care nurses and physicians from the same home care agency (94). In another study, a multi-component intervention prior to the delivery of care that involved implementation of facility-based palliative care teams, palliative and end-of-life staff education, rounds with a geropalliative care nurse practitioner and coaching from the nurse practitioner was associated with a decline in hospital deaths for working palliative care teams, but it had no influence on place of death. These working palliative care teams had a "clear and shared mission, a sense that the team influenced residents' care, and a perception of continued team sustainability" (95).

In rural areas, home care nurses acted as advocates for persons who wished to die at home. Thus, strong relationships with persons in their care and communication, support and the environment of care can influence the ability of nurses to support the preferences of persons, including the preference to die at home (96).

Values and Preferences

Families valued the multi-component program, which included two end-of-life coordination centres for the community, because it was found to improve access to care and equipment, and it provided flexibility in responding to the needs of persons and their families (90).

Health Equity

Despite the aforementioned evidence, the majority of Canadians do not receive formal palliative care outside of the hospital setting in their last 12 months of life (16). In a 2013 Canadian survey, 75 per cent of people reported a preference to die at home (98); however, when measured in 2015, only 15 per cent actually died at home, while 61 per cent died in hospital, 15 per cent died in another health care facility and 8 per cent died in another specified locality (16).

Barriers to access of palliative care and end-of-life care services are more pronounced for populations that are structurally vulnerable. For example, persons who are experiencing homelessness may not have the opportunity to die in a safe and secure place with access to family that will care for them (186). Persons living in rural and remote locations may also face barriers to access of palliative care and end-of-life services.

Expert Panel Justification of Recommendation

Several benefits were identified as a result of high-quality home and community palliative care and end-of-life care, and the expert panel attributed value to supporting persons to die at home if that is in alignment with their wishes. Despite the low certainty of the effects, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- It is important to assess each person's preference with regard to place of death, and reassess this preference based on their changing health and psychological status, needs and circumstances. Preferred place of death may change over time and can be influenced by the quality of care available, the access to home support and other services (e.g., volunteers) and impact on family caregivers (100). For more information regarding assessing the preferred place of death, see **Recommendation 2.2**.
- The expert panel highlighted that persons who have access to social support systems (e.g., family and friends) may choose home as a preferred place of death, so support also must be available to family caregivers (101).
- While surveys indicate that the majority of persons wish to die at home, other settings should be considered, such as an in-patient care unit, hospice or long-term care facility (17, 98). Access to alternative settings of care may be needed for persons whose preferred place of death changes later in their palliative care trajectory.
- For remote locations where geographical challenges exist, telemedicine represents one option to support an interprofessional approach to care at home. The expert panel also recognized that community agencies need to develop collaborative approaches to support comprehensive palliative home care.
- Refer to **Table 8** for details of interventions included within the research.

Table 8: Intervention Details

INTERVENTION	DETAILS
Hospice@Home (89)	■ After-hours community service provided by a multidisciplinary palliative care team. ■ Its goal is to support people to die at home if that is their preference, or to spend as much time at home before dying in an institution. Also seeks to detect and address barriers to end-of-life care within the community. ■ Available via telephone 24 hours a day, seven days a week. ■ Coordinated by registered nurses.
Marie Curie Nursing Service (91)	■ Hands-on home care and emotional support available. ■ Available after hours for both day and night shifts (nine-hour shifts). ■ Provided by registered nurses and health care assistants.

INTERVENTION	DETAILS
Delivering Choice Program (90)	■ Nursing service. ■ Two facilitators available to provide training to teams. ■ Intervention included several components: □ After-hours telephone line operated by palliative care nurses. □ Two hospital-based discharge nurses. □ Electronic end-of-life care register to record wishes of persons. □ Two end-of-life coordination centres for community referrals.
Improving Palliative Care through Teamwork (IMPACTT) (95)	■ Staff education and team development, followed by an intervention phase, in which care is provided by a family-based palliative care team.

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Costa V. The determinants of place of death: an evidence-based analysis [Internet]. Toronto (ON): Health Quality Ontario; 2014. Available from: http://www.hqontario.ca/Portals/0/Documents/evidence/reports/eba-eol-determinants-pod-1411-en.pdf	■ Evidence-based analysis of determinants of place of death.
Hospice Palliative Care Ontario (HPCO). Compassionate communities provincial strategy [Internet]. Toronto (ON): HPCO; [date unknown]. Available from: https://www.hpco.ca/wp-content/uploads/HPCO-Compassionate-Communties-Strategy-Final.pdf	■ Provincial strategy supporting whole person care throughout the province of Ontario in order to benefit patients, family caregivers and the formal health-care system.

RESOURCE	DESCRIPTION
Registered Nurses' Association of Ontario (RNAO). Care transitions [Internet]. Toronto (ON): RNAO; 2014. Available from: RNAO.ca/sites/rnao-ca/files/Care_Transitions_BPG.pdf (English) RNAO.ca/bpg/language/transitions-des-soins (French)	■ Provides evidence-based recommendations for nurses and interprofessional teams assessing and managing patients during transitions in care. ■ Based on the best available evidence; where evidence was limited, the recommendations were based on the consensus of expert opinion.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
24/7 On-Call Provincial Palliative Physician Service [Internet]. Edmonton (AB): Alberta Health Services; c2019. Available from: https://www.albertahealthservices.ca/info/page14556.aspx	■ Service that provides palliative physician support to physicians in urban and rural health-care settings in Alberta. ■ Gives physicians who treat patients at home or in the community the option of receiving expert palliative physician consult support as an alternative to relocating patients and their families to urban areas or other health-care facilities for palliative specialist care.
College of Physicians and Surgeons of Alberta. Continuity of care. 2nd rev. ed. [Internet]. Edmonton (AB): College of Physicians and Surgeons of Alberta; January 2018. Available from: http://cpsa.ca/wp-content/uploads/2015/07/AP_Continuity-of-Care.pdf	■ Advises physicians on promoting continuity of care in practice.
College of Physicians and Surgeons of British Columbia. Practice standard: care coverage outside regular office hours. Vancouver (BC): College of Physicians and Surgeons of British Columbia; 2018. Available from: https://www.cpsbc.ca/files/pdf/PSG-Care-Coverage-Outside-Regular-Office-Hours.pdf	■ Practice standard for physicians regarding care coverage outside regular office hours.

RESOURCE	DESCRIPTION
Launch a Compassionate Community. In: Pallium Canada [Internet]. Ottawa (ON): Pallium Canada; c2018. Available from: https://pallium.ca/work-with-us/launch-a-compassionate-community/ (Website available in English and French)	■ Compassionate Communities acknowledge that caregiving, dying, death and grieving are everyone's business and that they are best when they include health and social services along with community members and neighbours.
Ministry of Health–British Columbia. The provincial end-of-life care action plan for British Columbia [Internet]. Vancouver (BC): Ministry of Health–British Columbia; 2013. Available from: https://www.health.gov.bc.ca/library/publications/year/2013/end-of-life-care-action-plan.pdf	■ Includes priorities for providing coordinated end-of-life care.
ARTICLES	
Seow H, Barbera L, Pataky R, Lawson B, O'Leary E, Fassbender K et al. Does increasing home care nursing reduce emergency department visits at the end of life? A population-based cohort study of cancer decedents. J Pain Symptom Manage. 2016 Feb;51(2);204-12.	■ Examines the association between the home care nursing rate on the emergency department visit rate during the last six months of life.
Seow H, Brazil K, Sussman J, Pereira J, Marshall D, Austin PC et al. Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: a pooled analysis. BMJ. 2014 Jun 6;348:g3496. doi: 10.1136/bmj.g3496.	■ Examines the impact of specialist palliative care teams on patients being in hospital in the last two weeks of life, emergency department visits in the last two weeks of life and dying in hospital.

RECOMMENDATION QUESTION #3:

Should continuing education, targeted skills training and debriefing be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families?

Outcomes: Compassion fatigue; stress/distress; resilience

The following recommendations are applicable to nurses and the interprofessional health team who provide care to persons, their families and their caregivers.

RECOMMENDATION 3.1:

The expert panel recommends that health-service organizations provide education and skills training for nurses and the interprofessional health team related to self-care, including stress management and mitigation of compassion fatigue.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Very low

Discussion of Evidence:

Benefits and Harms

Generally, evidence supports that education and training regarding self-care may improve outcomes for health providers, such as reducing stress and mitigating compassion fatigue and burnout (24, 102–104). Formal approaches to education and training (i.e., those offered by the organization) may promote positive coping in nurses, enable recognition of the importance of self-care and allow nurses to practice skills related to self-care (24). Informal approaches (i.e., those obtained from team relationships, friends and family) also may be beneficial because they facilitate social interaction and foster mutually supportive relationships (24). See **Recommendation 3.2** for information about debriefing among health providers.

Within the literature, education and training programs varied with regards to structure, delivery and content. Refer to the Practice Notes for this recommendation (found below) for details regarding the specific interventions identified in the systematic review.

Education

Continuing education may allow health providers to improve their theoretical and applied knowledge and practice regarding self-care behaviours (105). Health provider improvement in knowledge and skills regarding self-care was associated with increased resilience and reduced stress (105), and it also may be associated with long-term decreases in both work-related stress and work disappointment (103). Education sessions have the potential to allow health providers to reflect on their previous caring experiences and engage in discussions with colleagues, which can increase their understanding of the emotional and existential reactions of persons with progressive life-limiting illnesses. After the education sessions, they also may be more confident in supporting persons who are in existential distress, which may subsequently increase work satisfaction (103). In addition, health providers may be more readily able to provide the care they desire to give, and trust and understanding may increase between colleagues (103).

Conversely, some health providers reported that education increased exhaustion and there was inadequate time to attend the educational sessions (e.g., they did not want to leave colleagues with an unmanageable workload) (103).

Skills Training

Skills-training interventions generally focused on **self-regulation**[G], coping and self-care for health providers, although they varied in approach and mode of delivery. Skills-training interventions led to health providers feeling more relaxed, practicing self-compassion and experiencing an increased ability to cope with workplace problems, manage stress and provide emotional support to persons at the end of life and their families (104, 106). A technology-enabled yoga therapy intervention that included components of meditation was found to be associated with a reduction in compassion fatigue (102), while an intervention combining education and meditation was found to be associated with increased compassion satisfaction (106). However, some health providers reported emotional difficulty at the start of meditation when they had a chance to reflect on how much they thought about others instead of thinking about themselves (106).

Alternatively, a mobile application that involved psycho-education and tools for self-assessment and symptom tracking was not found to impact levels of stress, compassion satisfaction and burnout (107). In fact, certain topics addressed in the application elicited feelings of anxiety or uneasiness among participants (e.g., topics that assessed compassion fatigue) (107).

Group-based Interventions

Group-based interventions for managing compassion fatigue and/or stress may be effective in supporting health providers. In one group-based education intervention, there was a decrease in **secondary traumatic stress**[G] as evidenced by a decline in secondary traumatisation scores and burnout scores measured on the ProQOL IV self-assessment. Compassion satisfaction scores, however, remained unchanged (108).

A mindfulness-based group intervention was found to decrease compassion fatigue (109). Similarly, a brief group intervention that aimed to build the skills of nurses in managing challenging situations via training manuals, learning modules and group support was associated with decreases in stress (110).

Values and Preferences

Within the literature, health providers were generally satisfied with skills-training interventions to mitigate and manage compassion fatigue, and they viewed them positively. Specifically, health providers gained knowledge regarding self-care strategies and recognized the value and relevance of the interventions used to address compassion fatigue (104, 108–110). As a result of interventions focused on mitigating compassion fatigue, some health providers reported that they were more likely to incorporate meditation into their lives, or they identified strategies that could be used at work or at home to make positive lifestyle changes (106, 108–110).

Health Equity

Not all health-service organizations will have access to the appropriate personnel, space and resources to implement continuing education and workplace skills-training interventions to mitigate compassion fatigue and workplace stress, particularly in remote areas where staff and resources are scarce (111). For instance, nurses reported various challenges to attending education and training courses, including high patient-to-nurse ratios and long-term lack of control and power, both of which impact their ability to engage in continuing education and contribute to feelings of disappointment at work (103). For programs delivered outside of work hours or in rural areas, there may be further accessibility challenges related to program availability, funding and travel (112, 113).

Expert Panel Justification of Recommendation

The expert panel attributed value to health-service organizations providing ongoing education and training related to self-care for health providers. The expert panel emphasized that compassion fatigue can affect all health providers in palliative care and end-of-life care, and that managing it should be a priority. There were both benefits and harms identified in the literature with respect to education and training for health provider self-care; however, the expert panel determined that health providers would value even small improvements in stress management and mitigations of compassion fatigue. Despite the very low certainty of evidence of effects, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- Education and skills training should also be extended to caregivers who may require additional support related to their self-care, including stress management and mitigation of compassion fatigue. See **Supporting Resources** for more information.
- Health service organizations are responsible for promoting access to education and training regarding self-care while also ensuring that adequate time is allotted for staff to engage in these offerings. Placing the responsibility on health providers themselves to access education and training may not be equitable due to program costs, time requirements, travel constraints and personal responsibilities. Support from the organization is required to ensure that all health providers have access to education and training programs (104).
- Management support is important: it allows health providers to take time off work to attend education sessions while ensuring that units are staffed in their absence and that funding is accessible (114).
- Strategies that nurses identify to support coping with the deaths of persons in their care include: education and programs; daily routines and activity, including personal coping strategies; and debriefing (see **Recommendation 3.2**) (115).
- See **Table 9** for the key components of the education and skills-training interventions found in the evidence.
- The expert panel acknowledges individuals may not be aware that they are experiencing compassion fatigue or stress. See **Appendix H** for a list of assessment tools that may assist health providers to recognize compassion fatigue and/or stress.

Table 9: Details of Interventions on Education and Skills Training from the Research Literature

INTERVENTION	DETAILS FROM THE RESEARCH LITERATURE
Continuing education	■ Content included information on emotional distress, clinical scenarios, relaxation techniques, reflection, stress management and communication strategies (103, 105). ■ Teaching/learning strategies included formal education, small group activities, role-playing, experiential learning, educational materials and discussion (105).
Skills training	■ Interventions generally focused on self-regulation, coping and self-care. ■ Interventions included: □ A technology-enabled yoga therapy intervention that included components of meditation. It was administered via smartphone to health providers in hospice and palliative care. The meditation sessions focused on breathing, attention and mental focus, with an aim to promote positive thoughts, reduce stress and increase self-awareness (102). □ One-on-one educational session for oncology nurses, followed by individual meditation five days per week (106). □ The Provider Resilience mobile app involved psycho-education on burnout, compassion satisfaction and stress, along with tools for self-assessment and symptom tracking. This intervention was not found to impact levels of stress, compassion satisfaction and burnout (107).
Group-based interventions	■ Interventions included: □ Educational components and small group activities, with an aim to promote resilience through self-regulation, self-validation and self-care (108). □ Principles of mindfulness-based stress reduction, education, experiential learning and practice at home (109). □ Brief group interventions aimed at building skills of nurses in managing challenging situations via training manual, learning modules and group support (110).

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Macmillan K, Peden J, Hopkinson J, et al. A caregiver's guide: a handbook about end of life care [Internet]. Ottawa (ON): The Military and Hospitaller Order of St. Lazarus of Jerusalem; 2004. Available from: https://hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf	■ A guide for caregivers assisting friends and family at the end of life.
Workplace Mental Health. In: Ontario Ministry of Labour [Internet]. Toronto (ON): Queen's Printer for Ontario; 2017 [updated July 2018]. Available from: https://www.labour.gov.on.ca/english/hs/mental_health.php (Website available in English and French)	■ Links to websites that have valuable information on mental health in the workplace.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Canadian Nurses Association (CNA). Nurse fatigue [Internet]. Ottawa (ON): CNA; 2012. Available from: https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/fact_sheet_nurse_fatigue_2012_e.pdf?la=en&hash=CF6B0942E8C1C16C96A60067860C9CA2E8C280B5 (English) https://www.cna-aiic.ca/-/media/cna/page-content/pdf-fr/fatigue_safety_2010_report_f.pdf?la=fr&hash=0DEA41C798A14F6DA2C9D006017ED2E88B9A7EDA (French)	■ Fact sheet regarding nurse fatigue.
Resources [Internet]. Topeka (KS): American Holistic Nurses Association; 2019. Available from: https://www.ahna.org/Resources	■ Resources on holistic care, stress management and self-care for nurses.
Welcome! In: The Free Mindfulness Project [Internet]. [place unknown]: The Free Mindfulness Project; [date unknown]. Available from: http://www.freemindfulness.org/	■ Collection of mindfulness mediation exercises and resources.

RECOMMENDATION 3.2:

The expert panel recommends that health-service organizations provide time and resources for nurses and the interprofessional health team to engage in debriefing.

Strength of the recommendation: Strong

Certainty of the evidence of effects: Very low

Confidence in the evidence: Low

Discussion of Evidence:

Benefits and Harms

Within the literature, debriefing included workplace meetings, support obtained through group clinical supervision and informal sessions between colleagues. Overall, evidence suggests that debriefing may be effective in allowing health providers to share feelings, process emotions, develop skills and provide support to one another (24, 116).

Qualitative literature indicates that monthly workplace support group meetings may present health providers with opportunities to develop communication strategies, discuss challenging situations, share resources and provide positive reinforcement to colleagues in a structured and safe environment (116). Support groups also may allow health providers to improve coping practices, express emotions, gain perspective, validate feelings (e.g., about grief and loss), improve work–life balance and manage stress (116).

Debriefing conducted through group clinical supervision was also identified within the literature. This process involved clinical supervision by trained registered nurses provided in a group setting, with the intention of helping health providers cope with demanding clinical situations, share experiences and connect with colleagues. Group clinical supervision was shown to be helpful in allowing health providers release emotions, reflect critically on events, learn from experiences, obtain support through conversations with colleagues, and improve coping and resilience (24).

Informal support from social networks and peers can also help health providers cope with work challenges and release stress by means of sharing experiences and emotions (24). Trusted team members can support each other through crisis, loss and frustration, while simultaneously providing understanding and acceptance (24). Team meetings can represent a way for health providers to share emotions and obtain support in a safe environment, but some health providers feel they do not have the appropriate skills to provide support to colleagues. This can be associated with lower levels of personal accomplishment (24).

Values and Preferences

Health providers value discussions with colleagues and opportunities to converse about their emotions (117). Within the literature, health providers had a preference for workplace support group meetings that were conducted outside of the direct workplace (e.g., on a different floor) (116). Some health providers desired monthly meetings, others felt the frequency of monthly meetings was not sufficient and some preferred the meetings to be held as needed (116, 117). While health providers valued support from friends and family with regards to care experiences, colleagues

were the preferred choice for debriefing due to a shared understanding of the environment, language and experiences encountered (24). Close relationships within teams and relationships that were built on trust, respect and openness were seen as facilitators for a supportive environment (24).

Health Equity

The expert panel acknowledged that support for workplace debriefing interventions will vary between health-service organizations depending on available resources, funding and staff. For programs held outside of working hours, individual factors—such as transportation issues, funding or competing personal responsibilities—may represent barriers to accessing debriefing support in the workplace (113). Alternatively, for debriefing interventions that are held during working hours, health providers report that workload relief for staff is required from organizations (113).

Expert Panel Justification of Recommendation

Several benefits were identified when health-service organizations provided time and resources for nurses and the interprofessional health team to engage in debriefing. Despite very low certainty of evidence of effects and low confidence in the evidence, the expert panel determined the strength of the recommendation to be strong.

Practice Notes

- The expert panel highlighted that debriefing could occur both formally and informally, and that both should be supported by health-service organizations and integrated into work-life culture. Please see the **Supporting Resources** and **Appendix M** for example debriefing tools.
- Debriefing should be conducted in a safe space and occur regularly, which can allow debriefing skills to develop over time.
- The expert panel proposed that health-service organizations should provide opportunities for health providers to engage in debriefing after the death of each person.
- Specific suggestions from the expert panel regarding debriefing include the following:
  - Time within the working day to do these activities, with costs and coverage away from patient care supported by the employer.
  - Training for some staff to take a lead on these activities.
  - Support from professionals who are knowledgeable (e.g., psychologists and social workers).
  - An awareness in the organization of the factors that contribute to the health and safety of its employees and the measures that can be taken to mitigate issues (e.g., staffing ratios).

Supporting Resources

RESOURCE	DESCRIPTION
ONTARIO-BASED RESOURCES	
Workplace Mental Health. In: Ontario Ministry of Labour [Internet]. Toronto (ON): Queen's Printer for Ontario; 2017 [updated July 2018]. Available from: https://www.labour.gov.on.ca/english/hs/mental_health.php (Website available in English and French)	■ Links to websites that have valuable information on mental health in the workplace.
RESOURCES FROM JURISDICTIONS OUTSIDE OF ONTARIO	
Eppich W, Cheng A. PEARLS scripted debriefing tool [Internet]. [place unknown]: American Heart Association; [date unknown]. Available from: https://www.heart.org/idc/groups/heart-public/@wcm/@hcm/@gwtg/documents/downloadable/ucm_486571.pdf	■ Framework for debriefing for health providers.
Mitchell JT. Critical incident stress debriefing (CISD) [Internet]. [place unknown]: Info Trauma; [date unknown]. Available from: http://www.info-trauma.org/flash/media-f/mitchellCriticalIncidentStressDebriefing.pdf	■ Critical Incident Stress Debriefing (CISD) is a specific, seven-phase, small group, supportive crisis intervention process.
PEARLS Healthcare Debriefing Tool. In: Debrief2Learn [Internet]. [place unknown]: Debrief 2 Learn; [date unknown]. Available from: https://debrief2learn.org/pearls-debriefing-tool/	■ A cognitive aid that supports educator training and addresses the phases of debriefing, associated objectives and tasks, and sample phrases. It also outlines performance domains and provides three approaches for analyzing clinical or simulated events. ■ Can be viewed electronically on a phone, tablet or computer, and printed as a pocket card or poster.

RESOURCE	DESCRIPTION
Quality Palliative Care in Long Term Care Alliance (QPC-LTC). Peer led debriefing toolkit: guidelines for promoting effective grief support among front line staff [Internet]. Thunder Bay (ON): QPC-LTC; [date unknown]. Available from: http://www.palliativealliance.ca/assets/files/Alliance_Reources/Org_Change/Peer_Led_Debriefing-_Final.pdf	■ Guidelines for promoting effective grief support among direct-care providers.
ARTICLES	
Sawyer T, Eppich W, Brett-Fleegler M, Grant V, Cheng A. More than one way to debrief: a critical review of healthcare simulation debriefing methods. Simul Healthc. 2016 Jun;11(3):209-17.	■ Review examining the timing, facilitation, conversational structures and process elements used in health-care simulation debriefing.

Research Gaps and Future Implications

The RNAO Best Practice Guideline Development and Research Team and expert panel identified priority areas for future research (outlined in **Table 10**). Studies conducted in these areas would provide further evidence to support high-quality and equitable support for persons at the end of life and their families. The list is not exhaustive; other areas of research may be required.

Table 10: Priority Research Areas for Each Recommendation Question

RECOMMENDATION QUESTION	PRIORITY RESEARCH AREA
RECOMMENDATION QUESTION #1: **Should an interprofessional approach be recommended for the provision of care to adults in the last 12 months of life?** **Outcomes: Person and family experience with care; effectiveness of provided care from the person and family perspective; access to care; coordination of care; transitions in care; effectiveness of provided care from health provider perspective**	■ Impact of interprofessional approaches to palliative care and end-of-life care on access to care, care transitions and coordination of care. ■ Impact of interprofessional approaches to care in rural or remote areas, including use of telemedicine and other technological resources. ■ Large-scale studies comparing different models and approaches to palliative and end-of-life care. ■ Examination of specialist and generalist interprofessional health team approaches, and new models of care delivery. ■ Examination of the role of Indigenous healers and elders as part of the interprofessional health team as it relates to palliative care and end-of-life care.
RECOMMENDATION QUESTION #2: **What nurse-led interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life?** **Outcomes: Support for spiritual care; support for emotional care; support for existential care; care in alignment with the person's wishes; culturally safe care; place of death**	■ Exploring the needs of persons in the last 12 months of life and their families in remote areas and Indigenous communities. ■ Studies evaluating outcomes from the perspective of the person experiencing the last 12 months of progressive life-limiting illness. ■ Exploring strategies to support cultural safety at the end of life. ■ Providing palliative care and end-of-life care to members of the 2SLGBTQI+ community, Indigenous persons, new immigrants, incarcerated individuals and persons experiencing homelessness. ■ Providing palliative care and end-of-life care in settings, such as long-term care and hospitals.

RECOMMENDATION QUESTION	PRIORITY RESEARCH AREA
RECOMMENDATION QUESTION #3: **Should continuing education, targeted skills training and debriefing be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families?** **Outcomes: Compassion fatigue; stress/ distress; resilience**	■ Long-term effectiveness of continuing education, targeted skills training and debriefing interventions for nurses and the interprofessional health team for promoting resilience and mitigation of compassion fatigue, stress and distress. ■ Effectiveness of continuing education, targeted skills training and debriefing on moral distress. ■ Evaluation of the effectiveness of structured and regular formal debriefing interventions. ■ Evaluation of the effectiveness of informal debriefing interventions. ■ Impact of continuing education, skills training and debriefing for the organization, including the economic impact. ■ An examination of various approaches to address compassion fatigue, stress and moral distress. ■ Translating continuing education into competency.
Evaluation (see Tables 3 and 4)	■ Development of public data repositories and indicators for provincial, national and international data collection of outcomes relevant to palliative care and end-of-life care. ■ Development of reliable and valid instruments that capture the quality of life and the needs of persons at the end of life across the care continuum. ■ Standardized palliative care and end-of-life care education and training for program monitoring and evaluation. ■ Measures of quality palliative care and end-of-life care in rural versus urban centres.

Implementation Strategies

Implementing BPGs at the point-of-care is multi-faceted and challenging. It takes more than awareness and distribution of BPGs for practice to change: BPGs must be adapted for each practice setting in a systematic and participatory way to ensure that recommendations fit the local context (118). The 2012 RNAO *Toolkit: Implementation of Best Practice Guidelines, Second Edition* provides an evidence-based process for doing this. It can be downloaded at RNAO.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition.

The *Toolkit* is based on emerging evidence that successful uptake of best practices in health care is more likely when the following occur:

- leaders at all levels are committed to supporting BPG implementation;
- BPGs are selected for implementation through a systematic, participatory process;
- stakeholders for whom the BPGs are relevant are identified and engaged in the implementation;
- environmental readiness for implementing BPGs is assessed;
- the BPG is tailored to the local context;
- barriers and facilitators to using the BPG are assessed and addressed;
- interventions to promote use of the BPG are selected;
- use of the BPG is systematically monitored and sustained;
- evaluation of the BPG's impact is embedded in the process; and
- there are adequate resources to complete all aspects of the implementation.

The *Toolkit* uses the "Knowledge-to-Action" framework (119) to demonstrate the process steps required for knowledge inquiry and synthesis (see **Figure 4**). It also guides the adaptation of the new knowledge to the local context and its implementation. This framework suggests identifying and using knowledge tools (such as BPGs) to identify gaps and begin the process of tailoring new knowledge to local settings.

RNAO is committed to widespread deployment and implementation of our BPGs. We use a coordinated approach to dissemination, incorporating a variety of strategies, including the following:

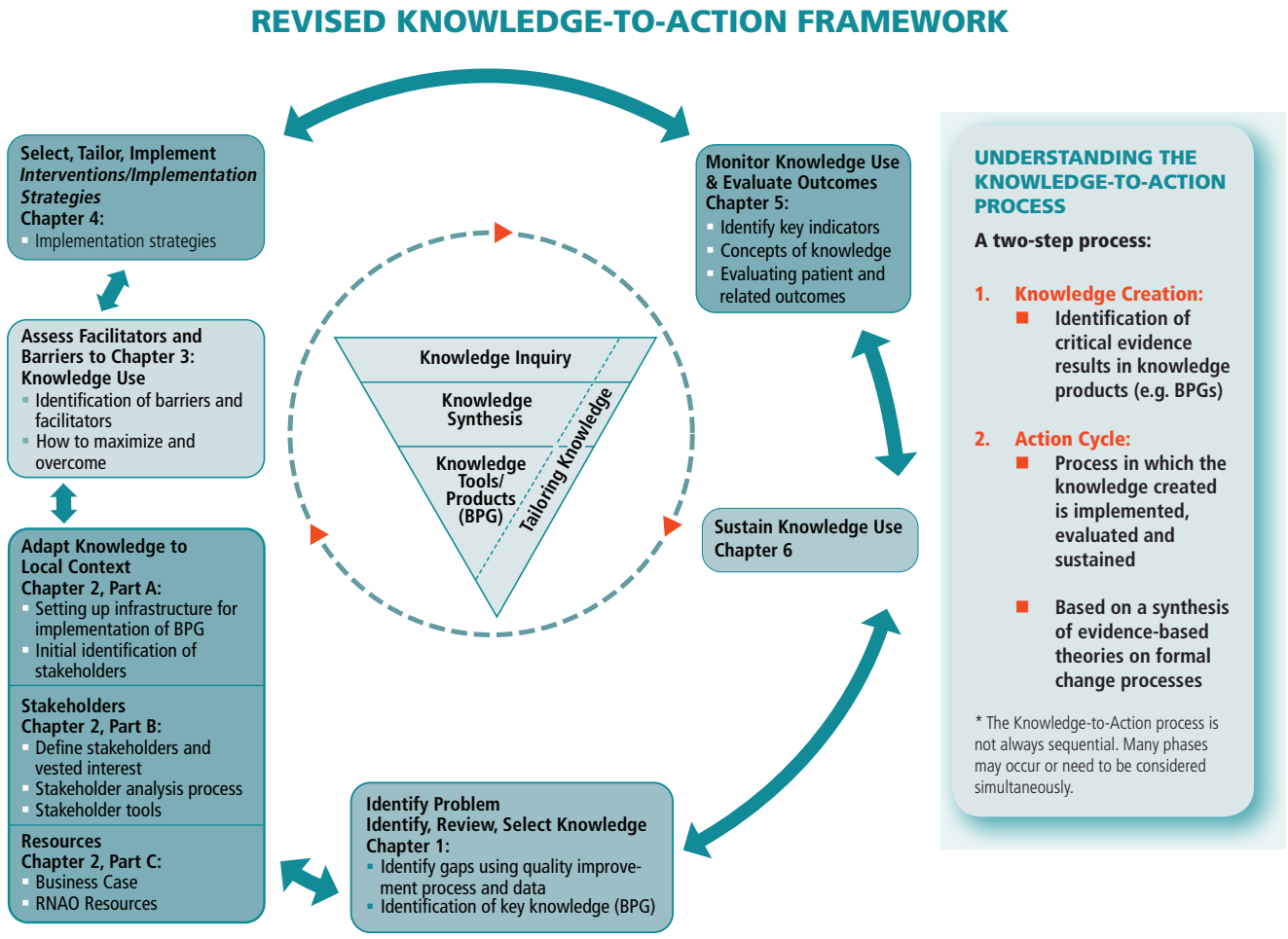
1. The Best Practice Champion Network®, which develops the capacity of individual nurses to foster awareness, engagement and adoption of BPGs.
2. The BPG Order Sets™ provide clear, concise and actionable intervention statements derived from practice recommendations. BPG Order Sets can be readily embedded within electronic records, but they also may be used in paper-based or hybrid environments.
3. The BPSO® designation, which supports implementation at the organization and system levels. BPSOs focus on developing evidence-based cultures with the specific mandate to implement, evaluate and sustain multiple RNAO BPGs.

In addition, we offer annual capacity-building learning institutes on specific BPGs and their implementation.

Information about our implementation strategies can be found at:

- RNAO Best Practice Champions Network®: RNAO.ca/bpg/get-involved/champions
- RNAO BPG Order Sets™: RNAO.ca/ehealth/bpgordersets
- RNAO BPSOs®: RNAO.ca/bpg/bpso
- RNAO capacity-building learning institutes and other professional development opportunities: RNAO.ca/events

Figure 4: Revised Knowledge-to-Action Framework



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References

1. Registered Nurses' Association of Ontario (RNAO). Toolkit: implementation of best practice guidelines, second edition [Internet]. Toronto (ON): RNAO; 2012. Available from: https://RNAO.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition

2. Registered Nurses' Association of Ontario (RNAO). End-of-life care during the last days and hours [Internet]. Toronto (ON): RNAO; 2011. Available from: https://RNAO.ca/sites/rnao-ca/files/End-of-Life_Care_During_the_Last_Days_and_Hours_0.pdf

3. Ontario Palliative Care Network (OPCN). Key palliative care concepts and terms [Internet]. Toronto (ON): OPCN; 2017. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/KEY_PALLIATIVE_CARE_CONCEPTS_AND_TERMS.pdf

4. Canadian Hospice Palliative Care Association (CHPCA). Lexicon of terms related to the integrated palliative approach to care [Internet]. Ottawa (ON): CHPCA; 2014. Available from: http://hpcintegration.ca/media/53072/TWF-lexicon-eng-final.pdf

5. Definitions. In: Family Caregiver Alliance National Center on Caregiving [Internet]. San Francisco (CA): Family Caregiver Alliance; 31 Jan 2014. Available from: https://www.caregiver.org/definitions-0

6. College of Nurses of Ontario (CNO). RHPA: scope of practice, controlled acts model [Internet]. Toronto (ON): CNO; 2018. Available from: http://www.cno.org/globalassets/docs/policy/41052_rhpascope.pdf

7. College of Nurses of Ontario (CNO). Working with unregulated care providers. Updated in 2013 [Internet]. Toronto (ON): CNO; 2013. Available from: http://www.cno.org/globalassets/docs/prac/41014_workingucp.pdf

8. Virani T. Interprofessional collaborative teams [Internet]. Ottawa (ON): Canadian Health Services Research Foundation; 2012. Available from: https://www.cfhi-fcass.ca/Libraries/Commissioned_Research_Reports/Virani-Interprofessional-EN.sflb.ashx

9. WHO Definition of Palliative Care. In: World Health Organization [Internet]. Geneva (CH): WHO; c2019. Available from: http://www.who.int/cancer/palliative/definition/en/

10. Canadian Hospice Palliative Care Association (CHPCA). A model to guide hospice palliative care: based on national principles and norms of practice [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf

11. Schunemann H, Brozek J, Guyatt G, Oxman A, editors. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach [Internet]. [place unknown]: The GRADE Working Group; 2013. Available from: http://gdt.guidelinedevelopment.org/app/handbook/handbook.html

12. Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M et al. Applying GRADECERQual to qualitative evidence synthesis findings: introduction to the series. Implementation Science. 2018;13(Suppl 1):2.

13. Donabedian A. Evaluating the quality of medical care. Milbank Q. 2005;83(4):691-729.

14. VandeVelde-Coke S, Doran D, Grinspun D, Hayes L, Sutherland Boal A, Velji K et al. Measuring outcomes of nursing care, improving the health of Canadians: NNQR (C), C-HOBIC and NQuiRE. Nurs Leadersh (Tor Ont). 2012;25(2):26-37.

15. Quality Hospice Palliative Care Coalition of Ontario. Advancing high quality, high value palliative care in Ontario. A declaration of partnership and commitment to action [Internet]. Toronto (ON): Queen's Printer for Ontario; 2011. Co-published by the Quality Hospice Palliative Care Coalition of Ontario. Available from: http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf

16. Canadian Institute for Health Information (CIHI). Access to palliative care in Canada [Internet]. Ottawa (ON): CIHI; 2018. Available from: https://www.cihi.ca/sites/default/files/document/access-palliative-care-2018-en-web.pdf

17. Health Quality Ontario (HQO). Palliative care at the end of life [Internet]. Toronto (ON): Queen's Printer for Ontario; 2016. Available from: http://www.hqontario.ca/Portals/0/documents/system-performance/palliative-care-report-en.pdf

18. Social determinants of health and health inequalities. In: Canada.ca [Internet]. Ottawa (ON): Government of Canada; [updated 25 Sep 2018]. Available from: https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health.html

19. Shimoinaba K, O'Connor M, Lee S, Kissane D. Developing relationships: a strategy for compassionate nursing care of the dying in Japan. Palliat Support Care. 2014;12(6):455-64.

20. Brach C, Fraser I. Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. Med Care Res Rev. 2000;57(Suppl 1):181-217.

21. Renzaho AM, Romios P, Crock C, Sønderlund AL. The effectiveness of cultural competence programs in ethnic minority patient-centered health care—a systematic review of the literature. Int J Qual Health Care. 2013;25(3):261-9.

22. Qureshi D, Tanuseputro P, Perez R, Pond GR, Seow HY. Early initiation of palliative care is associated with reduced late-life acute-hospital use: a population-based retrospective cohort study. Palliat Med. 2019;33(2):150-9.

23. Tanuseputro P, Wodchis WP, Fowler R, Walker P, Bai YQ, Bronskill SE et al. The health care cost of dying: a population-based retrospective cohort study of the last year of life in Ontario, Canada. PLoS One. 2015;10(3):e0121759.

24. Gillman L, Adams J, Kovac R, Kilcullen A, House A, Doyle C. Strategies to promote coping and resilience in oncology and palliative care nurses caring for adult patients with malignancy: a comprehensive systematic review. JBI Database System Rev Implement Rep. 2015;13(5):131-204.

25. Sorenson C, Bolick B, Wright K, Hamilton R. An evolutionary concept analysis of compassion fatigue. J Nurs Scholarsh. 2017;49(5):557-63.

26. Compassion fatigue. In: Merriam-Webster Dictionary [Internet]. Springfield (MA): Merriam-Webster; c2019. Available from: https://www.merriam-webster.com/dictionary/compassion%20fatigue

27. Zhang YY, Han WL, Qin W, Yin HX, Zhang CF, Kong C et al. Extent of compassion satisfaction, compassion fatigue and burnout in nursing: a meta-analysis. J Nurs Manag. 2018;26(7):810-9.

28. Perry B, Toffner G, Merrick T, Dalton J. An exploration of the experience of compassion fatigue in clinical oncology nurses. Can Oncol Nurs J. 2011;21(2):91-7.

29. Nolte AG, Downing C, Temane A, Hastings-Tolsma M. Compassion fatigue in nurses: a metasynthesis. J Clin Nurs. 2017;26(23-24):4364-78.

30. Wu S, Singh-Carlson S, Odell A, Reynolds G, Su Y. Compassion fatigue, burnout, and compassion satisfaction among oncology nurses in the United States and Canada. Oncol Nurs Forum. 2016;43(4):E161-9.

31. Halter M, Boiko O, Pelone F, Beighton C, Harris R, Gale J et al. The determinants and consequences of adult nursing staff turnover: a systematic review of systematic reviews. BMC Health Serv Res. 2017;17(1):824.

32. Kim Y, Han K. Longitudinal associations of nursing staff turnover with patient outcomes in long-term care hospitals in Korea. J Nurs Manag. 2018;26(5):518-24.

33. Rutter M. Resilience concepts and findings: implications for family therapy. J Fam Ther. 1999;21(2):119-44.

34. Awa WL, Plaumann M, Walter U. Burnout prevention: a review of intervention programs. Patient Educ Couns. 2010;78(2):184-90.

35. Grafton E, Gillespie B, Henderson S. Resilience: the power within. Oncol Nurs Forum. 2010;37(6).

36. Leclerc BS, Blanchard L, Cantinotti M, Couturier Y, Gervais D, Lessard S et al. The effectiveness of interdisciplinary teams in end-of-life palliative care: a systematic review of comparative studies. J Palliat Care. 2014;30(1):44-54.

37. DiScala SL, Onofrio S, Miller M, Nazario M, Silverman M. Integration of a clinical pharmacist into an interdisciplinary palliative care outpatient clinic. Am J Hosp Palliat Care. 2017;34(9):814-9.

38. Kobayashi R, McAllister CA. Similarities and differences in perspectives on interdisciplinary collaboration among hospice team members. Am J Hosp Palliat Care. 2014;31(8):825-32.

39. Bainbridge D, Brazil K, Krueger P, Ploeg J, Taniguchi A, Darnay J. Measuring horizontal integration among health care providers in the community: an examination of a collaborative process within a palliative care network. J Interprof Care. 2015;29(3):245-52.

40. Groh G, Vyhnalek B, Feddersen B, Führer M, Borasio GD. Effectiveness of a specialized outpatient palliative care service as experienced by patients and caregivers. J Palliat Med. 2013;16(8):848-56.

41. Douglas SL, Daly BJ. Effect of an integrated cancer support team on caregiver satisfaction with end-of-life care. Oncol Nurs Forum. 2014;41(4):E248-55.

42. Klarare A, Rasmussen BH, Fossum B, Fürst CJ, Hansson J, Hagelin CL. Experiences of security and continuity of care: patients' and families' narratives about the work of specialized palliative home care teams. Palliat Support Care. 2017;15(2):181-9.

43. Joseph R, Brown-Manhertz D, Ikwuazom S, Singleton JK. The effectiveness of structured interdisciplinary collaboration for adult home hospice patients on patient satisfaction and hospital admissions and re-admissions: a systematic review. JBI Database System Rev Implement Rep. 2016;14(1):108-39.

44. Khateeb R, Puelle MR, Firn J, Saul DA, Chang R, Min L. Interprofessional rounds improve timing of appropriate palliative care consultation on a hospitalist service. Am J Med Qual. 2018;33(6):569-75.

45. Gaudet A, Kelley ML, Williams AM. Understanding the distinct experience of rural interprofessional collaboration in developing palliative care programs. Rural Remote Health. 2014;14(2):2711.

46. Isaacson MJ, Minton ME. End-of-life communication: nurses cocreating the closing composition with patients and families. ANS Adv Nurs Sci. 2018;41(1):2-17.

47. Dudley N, Ritchie CS, Rehm RS, Chapman SA, Wallhagen MI. Facilitators and barriers to interdisciplinary communication between providers in primary care and palliative care. J Palliat Med. 2019;22(3):243-9.

48. Ciemins EL, Brant J, Kersten D, Mullette E, Dickerson D. Why the interdisciplinary team approach works: insights from complexity science. J Palliat Med. 2016;19(7):767-70.

49. Edwin AK, Johnson McGee S, Opare-Lokko EA, Gyakobo MK. A structured approach to end-of-life decision making improves quality of care for patients with terminal illness in a teaching hospital in Ghana. Am J Hosp Palliat Med. 2016;33(2):144-9.

50. Klarare A, Hagelin CL, Fürst CJ, Fossum B. Team interactions in specialized palliative care teams: a qualitative study. J Palliat Med. 2013;16(9):1062-9.

51. Lysaght Hurley S, Strumpf N, Barg FK, Ersek M. Not quite seamless: transitions between home and inpatient hospice. J Palliat Med. 2014;17(4):428-34.

52. Sun V, Grant M, Koczywas M, Freeman B, Zachariah F, Fujinami R et al. Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. Cancer. 2015;121(20):3737-45.

53. Ferrell B, Sun V, Hurria A, Cristea M, Raz DJ, Kim JY et al. Interdisciplinary palliative care for patients with lung cancer. J Pain Symptom Manage. 2015;50(6):758-67.

54. Huber K, Patel K, Garrigues S, Leff B, Ritchie C. Interdisciplinary teams and home-based medical care: secondary analysis of a national survey. J Am Med Dir Assoc. 2019 Feb 6. doi: 10.1016/j.jamda.2018.12.007. [Epub ahead of print.]

55. Miller SJ, Desai N, Pattison N, Droney JM, King A, Farquhar-Smith P et al. Quality of transition to end-of-life care for cancer patients in the intensive care unit. Ann Intensive Care. 2015;5(1):59.

56. Harstäde CW, Blomberg K, Benzein E, Östlund U. Dignity-conserving care actions in palliative care: an integrative review of Swedish research. Scand J Caring Sci. 2018;32(1):8-23.

57. Johnstone MJ, Hutchinson AM, Redley B, Rawson H. Nursing roles and strategies in end-of-life decision making concerning elderly immigrants admitted to acute care hospitals: an Australian study. J Transcult Nurs. 2016;27(5):471-9.

58. Butler M, McCreedy E, Schwer N, Burgess D, Call K, Przedworski J et al. Improving cultural competence to reduce health disparities [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2016. (Comparative Effectiveness Reviews, No. 170.) 1, Introduction. Available from: https://www.ncbi.nlm.nih.gov/books/NBK361130/

59. Understanding the report on Key Health Inequalities in Canada. In: Canada.ca [Internet]. Ottawa (ON): Government of Canada; [modified 24 Apr 2019]. Available from: https://www.canada.ca/en/public-health/services/publications/science-research-data/understanding-report-key-health-inequalities-canada.html

60. Martin EM, Barkley TW Jr. Improving cultural competence in end-of-life pain management. Nursing. 2016 Jan;46(1):32-41.

61. Cloyes KG, Hull W, Davis A. Palliative and end-of-life care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and their caregivers. Semin Oncol Nurs. 2018;34(1):60-71.

62. Fields A, Finucane AM, Oxenham D. Discussing preferred place of death with patients: staff experiences in a UK specialist palliative care setting. Int J Palliat Nurs. 2013;19(11):558-65.

63. Dyar S, Lesperance M, Shannon R, Sloan J, Colon-Otero G. A nurse practitioner directed intervention improves the quality of life of patients with metastatic cancer: results of a randomized pilot study. J Palliat Med. 2012;15(8):890-5.

64. Canadian Institute for Health Information (CIHI). Health care use at the end-of-life in western Canada [Internet]. Ottawa (ON): CIHI; 2007. Available from: https://secure.cihi.ca/free_products/end_of_life_report_aug07_e.pdf

65. Deaths, by place of death (hospital or non-hospital). In: Statistics Canada [Internet]. Ottawa (ON): Statistics Canada. 2013 - [cited on 25 Apr 2018]. Available from: http://www5.statcan.gc.ca/cansim/a26?lang=eng&id=1020509

66. Viitala A, Saukkonen M, Lehto JT, Palonen M, Åstedt-Kurki P. The coping and support needs of incurable cancer patients. J Hosp Palliat Care. 2018;20(2):187-94.

67. Auriemma CL, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D et al. Stability of end-of-life preferences: a systematic review of the evidence. JAMA Intern Med. 2014;174(7):1085-92.

68. Evans R, Finucane A, Vanhegan L, Arnold E, Oxenham D. Do place-of-death preferences for patients receiving specialist palliative care change over time? Int J Palliat Nurs. 2014;20(12):579-83.

69. Keall R, Clayton JM, Butow P. How do Australian palliative care nurses address existential and spiritual concerns? Facilitators, barriers and strategies. J Clin Nurs. 2014;23(21-22):3197-205.

70. Taylor EJ, Brander P. Hospice patient and family carer perspectives on nurse spiritual assessment. J Hosp Palliat Nurs. 2013;15(6):347-54.

71. Nixon AV, Narayanasamy A, Penny V. An investigation into the spiritual needs of neuro-oncology patients from a nurse perspective. BMC Nurs. 2013;12(1):2.

72. Walker H, Waterworth S. New Zealand palliative care nurses experiences of providing spiritual care to patients with life-limiting illness. Int J Palliat Nurs. 2017;23(1):18-26.

73. Tornøe KA, Danbolt LJ, Kvigne K, Sørlie V. The power of consoling presence—hospice nurses' lived experience with spiritual and existential care for the dying. BMC Nurs. 2014;13:25.

74. Rydé K, Hjelm K. How to support patients who are crying in palliative home care: an interview study from the nurses' perspective. Prim Health Care Res Dev. 2016;17(5):479-88.

75. O'Brien MR, Kinloch K, Groves KE, Jack BA. Meeting patients' spiritual needs during end-of-life care: a qualitative study of nurses' and healthcare professionals' perceptions of spiritual care training. J Clin Nurs. 2019;28(1-2):182-9.

76. Siler S, Mamier I, Winslow BW, Ferrell BR. Interprofessional perspectives on providing spiritual care for patients with lung cancer in outpatient settings. Oncol Nurs Forum. 2019;46(1):49-58.

77. Mehta A, Chan LS. Understanding of the concept of "total pain": a prerequisite for pain control. J Hosp Palliat Nurs. 2008;10(1):26-32.

78. Ronaldson S, Hayes L, Aggar C, Green J, Carey M. Palliative care nurses' spiritual caring interventions: a conceptual understanding. Int J Palliat Nurs. 2017;23(4):194-201.

79. Namasivayam P, Lee S, O'Connor M, Barnett T. Caring for families of the terminally ill in Malaysia from palliative care nurses' perspectives. J Clin Nurs. 2014;23(1-2):173-80.

80. Kwan CW, Ng MS, Chan CW. The use of life review to enhance spiritual well-being in patients with terminal illnesses: an integrative review. J Clin Nurs. 2017;26(23-24):4201-11.

81. Keall RM, Butow PN, Steinhauser KE, Clayton JM. Nurse-facilitated preparation and life completion interventions are acceptable and feasible in the Australian palliative care setting: results from a phase 2 trial. Cancer Nurs. 2013;36(3):E39-46.

82. Keall RM, Clayton JM, Butow PN. Therapeutic life review in palliative care: a systematic review of quantitative evaluations. J Pain Symptom Manage. 2015;49(4):747-61.

83. Keall R, Clayton JM, Butow P. Australian palliative care nurses' reflections on existential/spiritual interventions. J Hosp Palliat Nurs. 2014;16(2):105-12.

84. Kälvemark S, Höglund AT, Hansson MG, Westerholm P, Arnetz B. Living with conflicts—ethical dilemmas and moral distress in the health care system. Soc Sci Med. 2004;58(6):1075-84.

85. O'Neill CS, Yaqoob M, Faraj S, O'Neill CL. Nurses' care practices at the end of life in intensive care units in Bahrain. Nurs Ethics. 2017;24(8):950-61.

86. Bonavita A, Yakushko O, Morgan Consoli ML, Jacobsen S, Mancuso RL. Receiving spiritual care: experiences of dying and grieving individuals. OMEGA (Westport). 2018 Mar;76(4):373-94.

87. Kincheloe DD, Stallings Welden LM, White A. A spiritual care toolkit: an evidence-based solution to meet spiritual needs. J Clin Nurs. 2018;27(7-8):1612-20.

88. Mixer SJ, Fornehed ML, Varney J, Lindley LC. Culturally congruent end-of-life care for rural Appalachian people and their families. J Hosp Palliat Nurs. 2014;16(8):526-35.

89. Baird-Bower D, Roach J, Andrews M, Onslow F, Curnin E. Help is just a phone call away: after-hours support for palliative care patients wishing to die at home. Int J Palliat Nurs. 2016;22(6):286-91.

90. Purdy S, Lasseter G, Griffin T, Wye L. Impact of the Marie Curie Cancer Care Delivering Choice Programme in Somerset and North Somerset on place of death and hospital usage: a retrospective cohort study. BMJ Support Palliat Care. 2015;5(1):34-9.

91. Chitnis XA, Georghiou T, Steventon A, Bardsley MJ. Effect of a home-based end-of-life nursing service on hospital use at the end of life and place of death: a study using administrative data and matched controls. BMJ Support Palliat Care. 2013;3(4):422-30.

92. Naruse T, Yamamoto N, Sugimoto T, Fujisaki-Sakai M, Nagata S. The association between nurses' coordination with physicians and clients' place of death. Int J Palliat Nurs. 2017;23(3):136-42.

93. Sasao S, Tanabe K, Morita T, Takahashi T, Yasuda H, Kashii T et al. Facility-related factors influencing the place of death and home care rates for end-stage cancer patients. J Palliat Med. 2015;18(8):691-6.

94. Kiyanda BG, Dechêne G, Marchand R. Dying at home: experience of the Verdun local community service centre. Can Fam Physician. 2015;61(4):e215-8.

95. Temkin-Greener H, Mukamel DB, Ladd H, Ladwig S, Caprio TV, Norton SA et al. Impact of nursing home palliative care teams on end-of-life outcomes. Med Care. 2018;56(1):11-8.

96. Reed FM, Fitzgerald L, Bish MR. District nurse advocacy for choice to live and die at home in rural Australia: a scoping study. Nurs Ethics. 2015;22(4):479-92.

97. Klinger CA, Howell D, Marshall D, Zakus D, Brazil K, Deber RB. Resource utilization and cost analyses of home-based palliative care service provision: the Niagara West End-of-life Shared-Care Project. Palliat Med. 2013;27(2):115-22.

98. Canadian Hospice Palliative Care Association (CHPCA). What Canadians say: the way forward survey report. December 2013 [Internet]. Ottawa (ON): CHPCA; 2013. Available from: http://www.hpcintegration.ca/media/51032/The%20Way%20Forward%20-%20What%20Canadians%20Say%20-%20Survey%20Report%20Final%20Dec%202013.pdf

99. Arnup K. Death, dying and Canadian families [Internet]. Ottawa (ON): The Vanier Institute of the Family; 2013. Available from: http://vanierinstitute.ca/wp-content/uploads/2015/12/CFT_2013-11-00_EN.pdf

100. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. BMC Palliat Care. 2013;12:7.

101. Thomas C, Morris SM, Clark D. Place of death: preferences among cancer patients and their carers. Soc Sci Med. 2004;58(12):2431-44.

102. Heeter C, Lehto R, Allbritton M, Day T, Wiseman M. Effects of a technology-assisted meditation program on healthcare providers' interoceptive awareness, compassion fatigue, and burnout. J Hosp Palliat Nurs. 2017;19(4):314-22.

103. Udo C, Danielson E, Henoch I, Melin-Johansson C. Surgical nurses' work-related stress when caring for severely ill and dying patients in cancer after participating in an educational intervention on existential issues. Eur J Oncol Nurs. 2013;17(5):546-53.

104. Wentzel D, Brysiewicz P. Integrative review of facility interventions to manage compassion fatigue in oncology nurses. Oncol Nurs Forum. 2017;44(3):E124-40.

105. Lim HA, Tan JY, Liu J, Chua J, Ang EN, Kua EH et al. Strengthening resilience and reducing stress in psychosocial care for nurses practicing in oncology settings. J Contin Educ Nurs. 2016;47(1):8-10.

106. Hevezi JA. Evaluation of a meditation intervention to reduce the effects of stressors associated with compassion fatigue among nurses. J Holist Nurs. 2016;34(4):343-50.

107. Jakel P, Kenney J, Ludan N, Miller PS, McNair N, Matesic E. Effects of the use of the provider resilience mobile application in reducing compassion fatigue in oncology nursing. Clin J Oncol Nurs. 2016;20(6):611-6.

108. Potter P, Berger JA, Olsen S. Evaluation of a compassion fatigue resiliency program for oncology nurses. Oncol Nurs Forum. 2013;40(2):180-7.

109. Duarte J, Pinto-Gouveia J. Effectiveness of a mindfulness-based intervention on oncology nurses' burnout and compassion fatigue symptoms: a non-randomized study. Int J Nurs Stud. 2016;64:98-107.

110. Traeger L, Park ER, Sporn N, Repper-DeLisi J, Convery MS, Jacobo M et al. Development and evaluation of targeted psychological skills training for oncology nurses in managing stressful patient and family encounters. Oncol Nurs Forum. 2013;40(4):E327-36.

111. Lehmann U, Dieleman M, Martineau T. Staffing remote rural areas in middle- and low-income countries: a literature review of attraction and retention. BMC Health Serv Res. 2008;8(1):19.

112. Curran VR, Fleet L, Kirby F. Factors influencing rural health care professionals' access to continuing professional education. Aust J Rural Health. 2006;14(2):51-5.

113. Fink RM, Oman KS, Youngwerth J, Bryant LL. A palliative care needs assessment of rural hospitals. J Palliat Med. 2013;16(6):638-44.

114. Altounji D, Morgan H, Grover M, Daldumyan S, Secola R. A self-care retreat for pediatric hematology oncology nurses. J Pediatr Oncol Nurs. 2013;30(1):18-23.

115. Zheng R, Lee SF, Bloomer MJ. How nurses cope with patient death: a systematic review and qualitative meta-synthesis. J Clin Nurs. 2018;27(1-2):e39-49.

116. Wittenberg-Lyles E, Goldsmith J, Reno J. Perceived benefits and challenges of an oncology nurse support group. Clin J Oncol Nurs. 2014;18(4):E71-5.

117. Browning ED, Cruz JS. Reflective debriefing: a social work intervention addressing moral distress among ICU nurses. J Soc Work End Life Palliat Care. 2018;14(1):44-72.

118. Harrison M, Graham I, Fervers B. Adapting knowledge to local context. In Straus SE, Tetroe J, Graham I, editors. Knowledge translation in health care: moving from evidence to practice. Chichester (UK): John Wiley & Sons; 2013. p. 110-20.

119. Straus S, Tetroe J, Graham ID. Monitoring and evaluating knowledge. In Straus SE, Tetroe J, Graham ID, editors. Knowledge translation in health care. Oxford (UK): Wiley-Blackwell; 2009. p. 151-9.

120. Belief. In: APA Dictionary of Psychology [Internet]. Washington (DC): American Psychological Association; c2018. Available from: https://dictionary.apa.org/belief

121. Grief and bereavement. In: cancer.ca [Internet]. Toronto (ON): Canadian Cancer Society; c2019. Available from: http://www.cancer.ca/en/cancer-information/cancer-journey/advanced-cancer/grief-bereavement/?region=on

122. Rey M, Grinspun D, Costantini L, Lloyd M. The anatomy of a rigorous best practice guideline development process. In: Grinspun D, Bajnok I, editors. Transforming nursing through knowledge. Indianapolis (IN): Sigma Theta Tau International; 2018. p. 31-68.

123. Burnout. In: Merriam-Webster Dictionary [Internet]. Springfield (MA): Merriam-Webster; c2019. Available from: https://www.merriam-webster.com/dictionary/burnout

124. McDonald KM, Sundaram V, Bravata DM, Lewis R, Lin N, Kraft SA et al. Closing the quality gap: a critical analysis of quality improvement strategies (Vol. 7: care coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007. (Technical Reviews, No. 9.7.) Available from: https://www.ncbi.nlm.nih.gov/books/NBK44015/

125. Lewin S, Glenton C, Munthe-Kaas H, Carlsen B, Colvin CJ, Gülmezoglu M et al. Using qualitative evidence in decision making for health and social interventions: an approach to assess confidence in findings from qualitative evidence syntheses (GRADE–CERQual). PLoS Med. 2015;12(10):1-18.

126. Grove SK, Burns N, Gray J. The practice of nursing research: appraisal, synthesis, and generation of evidence. 7th ed. Toronto (ON): Elsevier Canada Health Sciences; 2012.

127. Avella JR. Delphi panels: research design, procedures, advantages, and challenges. IJDS. 2016;11:305-21.

128. Culturally Sensitive Care. In: College of Nurses of Ontario (CNO) [Internet]. Toronto (ON): CNO; [updated 13 Dec 2018]. Available from: http://www.cno.org/en/learn-about-standards-guidelines/educational-tools/ask-practice/culturally-sensitive-care/

129. Managing personal, emotional, cultural and spiritual needs in palliative care. In: health.vic [Internet]. Victoria (AU): Victoria State Government; c2018. Available from: https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/older-people/palliative/palliative-emotional

130. Williams R. Cultural safety—what does it mean for our work practice? Aust N Z J Public Health. 1999;23(2):213-4.

131. Nursing Council of New Zealand. Guidelines for cultural safety, the treaty of Waitangi, and Maori health in nursing and midwifery education and practice 2011 update [Internet]. Wellington (NZ): Nursing Council of New Zealand; 2005. Available from: http://www.nursingcouncil.org.nz/index.php/content/download/721/2871/file/Guidelines%20for%20cultural%20safety,%20the%20Treaty%20of%20Waitangi,%20and%20Maori%20health%20in%20nursing%20education%20and%20practice.pdf

132. Vaithilingam N, Jain S, Davies D. Helping the helpers: debriefing following an adverse incident. The Obstetrician & Gynaecologist. 2008;10(4):251-6.

133. Dijkers M. Introducing GRADE: a systematic approach to rating evidence in systematic reviews and to guideline development. KT Update. 2013;1(5):1-9.

134. Swain N, Gale C. A communication skills intervention for community healthcare workers reduces perceived patient aggression: a pretest-postest study. Int J Nurs Stud. 2014;51(9):1241-5.

135. Hecker, S. Education and training - introduction and overview. In: Stellman, JM, Gillespie, RM, editors. Encyclopaedia of occupational health & safety. International Labour Organization; 2015. Available from: http://www.iloencyclopaedia.org/part-iii/education-and-training/item/87-introduction-and-overview.

136. Treatment effect. In: GET-IT Glossary [Internet]. [place unknown]: GET IT; [date unknown]. Available from: https://getitglossary.org/term/effect,%20treatment

137. Emotion. In: APA Dictionary of Psychology [Internet]. Washington (DC): American Psychological Association; c2019. Available from: https://dictionary.apa.org/emotion

138. General Medical Council. Treatment and care towards the end of life: good practice in decision making. Manchester (UK): General Medical Council; 2010.

139. Effect estimate. In: GET-IT Glossary [Internet]. [place unknown]: GET IT; [date unknown]. Available from: https://getitglossary.org/term/effect+estimate

140. Stevens KR. The impact of evidence-based practice in nursing and the next big ideas. Online J Issues Nurs. 2013;18(2):4.

141. Cohen SR, Mount BM, Tomas JJ, Mount LF. Existential well-being is an important determinant of quality of life: evidence from the McGill Quality of Life Questionnaire. Cancer. 1996;77(3):576-86.

142. About Us [Internet]. In: The Gold Standards Framework [Internet]. London (UK): Gold Standards Framework; [updated 16 Feb 2017]. Available from: http://www.goldstandardsframework.org.uk/about-us

143. Tryselius K, Benzein E, Persson C. Ideas of home in palliative care research: a concept analysis. Nurs Forum. 2018;53(3):383-91.

144. Registered Nurses' Association of Ontario (RNAO). Person- and family-centered care [Internet]. Toronto (ON): RNAO; 2015. Available from: https://rnao.ca/bpg/guidelines/person-and-family-centred-care

145. College of Physicians and Surgeons of Ontario. Medical assistance in dying [Internet]. Toronto (ON): College of Physicians and Surgeons of Ontario; 2018. Available from: https://www.cpso.on.ca/Physicians/Policies-Guidance/Policies/Medical-Assistance-in-Dying

146. Glossary. Cochrane Community [Internet]. [place unknown]: Cochrane Collaboration; c2019. Available from: http://community.cochrane.org/glossary

147. Cullum N, Spilsbury K, Richardson G. Nurse led care. BMJ. 2005;330(7493):682-3.

148. Preference. In: Merriam-Webster Dictionary [Internet]. Springfield (MA): Merriam-Webster; 2018. Available from: https://www.merriam-webster.com/dictionary/preference

149. Austin Z, Sutton J. Qualitative research: getting started. Can J Hosp Pharm. 2014;67(6):436-40.

150. Rockers PC, Røttingen JA, Shemilt I, Tugwell P, Bärnighausen T. Inclusion of quasi-experimental studies in systematic reviews of health systems research. Health Policy. 2015;119(4):511-21.

151. What is Relational Coordination? In: Brandeis University: The Heller School [Internet]. Waltham (MA): Relational Coordination Research Collaborative; c2019. Available from: https://heller.brandeis.edu/relational-coordination/about-rc/index.html

152. Armstrong R, Hall BJ, Doyle J, Waters E. Scoping the scope of a Cochrane review. J Public Health (Oxf). 2011;33(1):147-50.

153. Figley CR. Compassion fatigue: coping with secondary traumatic stress disorder in those who treat the traumatized. New York (NY): Brunner/Mazel; 1995.

154. Self-regulation. In: APA Dictionary of Psychology [Internet]. Washington (DC): American Psychological Association; c2018. Available from: https://dictionary.apa.org/self-regulation

155. Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P et al. Shared decision making: a model for clinical practice. J Gen Intern Med. 2012;27(10):1361-7.

156. Légaré F, Stacey D, Turcotte S, Cossi MJ, Kryworuchko J, Graham ID et al. Interventions for improving the adoption of shared decision making by healthcare professionals. Cochrane Database Syst Rev. 2014(9):CD006732.

157. National Voices. Prioritising person-centred care: supporting shared decision-making [Internet]. London (UK): National Voices; 2014. Available from: https://www.nationalvoices.org.uk/sites/default/files/public/publications/supporting_shared_decision-making.pdf

158. Social determinants of health: Key concepts. In: World Health Organization (WHO) [Internet]. Geneva (Switzerland): WHO; c2019. Available from: https://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/

159. European Association for Palliative Care (EAPC). EAPC Task Force on Spiritual Care in Palliative Care [Internet]. [place unknown]: EPAC; [date unknown]. Available from: http://www.eapcnet.eu/Themes/ProjectsTaskForces/EAPCTaskForces/SpiritualCareinPalliativeCare.aspx

160. Baker CM, Ogden SJ, Prapaipanich W, Keith CK, Beattie LC, Nickleson LE. Hospital consolidation. Applying stakeholder analysis to merger life-cycle. J Nurs Adm. 1999;29(3):11-20.

161. Glossary of Terms. In: Speak Up Ontario [Internet]. Toronto (ON): Speak Up Ontario; c2019. Available from: https://www.speakupontario.ca/resource/glossary/

162. Value. In: APA Dictionary of Psychology [Internet]. Washington (DC): American Psychological Association; c2018. Available from: https://dictionary.apa.org/value

163. Wish. In: Merriam-Webster Dictionary [Internet]. Springfield (MA): Merriam-Webster; c2019. Available from: https://www.merriam-webster.com/dictionary/wish

164. Canadian Nurses Association (CNA). Advanced nursing practice: a national framework [Internet]. Ottawa (ON): CNA; 2008. Available from: https://www.cna-aiic.ca/en/~/media/nurseone/page-content/pdf-en/anp_national_framework_e

165. MacDonald J, Silva-Galleguillos A, Diaz OLG, Bajnok I. Enhancing the evidence-based nursing curriculum and competence in evidence-based practice. In: Grinspun D, Bajnok I, editors. Transforming nursing through knowledge: best practices for guideline development, implementation science, and evaluation. Indianapolis (IN): Sigma; 2018.

166. Monaghan T. A critical analysis of the literature and theoretical perspectives on theory-practice gap amongst newly qualified nurses within the United Kingdom. Nurse Educ Today. 2015;35(8):e1-7.

167. Smith SJ, Barry DG. The use of high-fidelity simulation to teach home care nursing. West J Nurs Res. 2013;35(3):297-312.

168. Browning M, Pront L. Supporting nursing student supervision: an assessment of an innovative approach to supervisor support. Nurse Educ Today. 2015;35(6):740-5.

169. Price S, Reichert C. The importance of continuing professional development to career satisfaction and patient care: meeting the needs of novice to mid- to late-career nurses throughout their career span. Adm Sci. 2017;7(17):1-13.

170. Palis AG, Quiros PA. Adult learning principles and presentation pearls. Middle East Afr J Ophthalmol. 2014;21(2):114-22.

171. Eggenberger E, Heimerl K, Bennet MI. Communication skills training in dementia care: a systematic review of effectiveness, training content, and didactic methods in different care settings. Int Psychogeriatr. 2013;25(3):345-58.

172. Yanamadala M, Wieland D, Heflin MT. Educational interventions to improve recognition of delirium: a systematic review. J Am Geriatr Soc. 2013;61(11):1983-93.

173. Grinspun D, McConnell H, Virani T, Squires J. Forging the way with implementation science. In: Grinspun D, Bajnok I, editors. Transforming nursing through knowledge: best practices for guideline development, implementation science, and evaluation. Indianapolis (IN): Sigma; 2018.

174. Thompson L, editor. Accreditation Canada NQuIRE International Advisory Council (IAC) meeting. Toronto (ON): [publisher unknown]; Apr 2018.

175. Accreditation overview. In: Accreditation Canada [Internet]. Ottawa (ON): Accreditation Canada; c2019. Available from: https://accreditation.ca/accreditation/

176. Marnocha S, Westphal J, Cleveland B. Pilot program to mentor nurse leaders for the future [Internet]. 2016 Sep 30. Madison (WI): Wisconsin Nurses Association; 2016. Available from: https://wisconsinnurses.org/mentor-nurse-leaders-program/

177. Brouwers MC, Kho ME, Browman GP, Burgers JS, Cluzeau F, Feder G et al. AGREE II: advancing guideline development, reporting and evaluation in health care. Can Med Assoc J. 2010;182(18):E839-42.

178. Higgins JP, Sterne JA, Savovi- J, Page MJ, Hróbjartsson A, Boutron I et al. A revised tool for assessing risk of bias in randomized trials. Cochrane Database Syst Rev. 2016;10(Suppl 1):29-31.

179. Sterne JAC, Hernán MA, Reeves BC, Savovi- J, Berkman ND, Viswanathan M et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. BMJ. 2016 Oct 12;355:i4919.

180. Shea BJ, Reeves BC, Wells G, Thuku M, Hamel C, Moran J et al. AMSTAR 2: a critical appraisal tool for systematic reviews that include randomised or non-randomised studies of healthcare interventions, or both. BMJ. 2017;358:j4008.

181. Critical Appraisal Skills Programme (CASP). CASP qualitative checklist [Internet]. Oxford (UK): CASP; 2018. Available from: https://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-2018_fillable_form.pdf

182. Guyatt G, Oxman AD, Akl EA, Kunz R, Vist G, Brozek J et al. GRADE guidelines: 1. Introduction—GRADE evidence profiles and summary of findings tables. J Clin Epidemiol. 2011;64(4):383-94.

183. GRADEprolGDT. In: gradepro.org [Internet]. [place unknown]: McMaster University and Evidence Prime Inc.; c2015. Available from: https://gradepro.org/

184. Guyatt GH, Oxman AD, Kunz R, Falck-Ytter Y, Vist GE, Liberati A et al. GRADE: going from evidence to recommendations. BMJ. 2008;336:1049-51.

185. Balshem H, Helfand M, Schünemann HJ, Oxman AD, Kunz R, Brozek J et al. GRADE guidelines: 3. Rating the quality of evidence. J Clin Epidemiol. 2011;64(4):401-6.

186. Stajduhar KI, Mollison A, Giesbrecht M, et al. "Just too busy living in the moment and surviving": barriers to accessing health care for structurally vulnerable populations at end-of-life. BMC Palliative Care. 2019; 18(11).

187. Klop HT, deVeer AJE, van Dongen SI. Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. BMC Palliative Care. 2018; 17(67).

Appendix A: Glossary of Terms

Advance care planning: "In Ontario, advance care planning is an iterative process that involves the mentally capable patient:

- **IDENTIFYING** their future Substitute Decision Maker by either
  - **Confirming** their satisfaction with their default/automatic Substitute Decision Maker in the Substitute Decision Maker hierarchy list in the Health Care Consent Act OR
  - **Choosing** someone else to act as Substitute Decision Maker by preparing a Power of Attorney for Personal Care (a formal written document).
- **SHARING** their wishes, values, and beliefs through conversations with the SDM and others that clarify their wishes, values and beliefs, and more generally how they would like to be cared for in the event of incapacity to give or refuse consent.

Rather than being a single event, advance care planning is ongoing and dynamic, with the potential for personal preferences to change over time as health status changes. It may be initiated at any point in the health care process, and may involve individuals who are currently healthy" (3, emphasis original).

Belief: "Acceptance of the truth, reality, or validity of something (e.g., a phenomenon, a person's veracity), particularly in the absence of substantiation" (120).

Bereavement: "The state of having suffered the loss of a loved one. It is the time after a loss during which grief is experienced and mourning occurs" (121).

Best practice guideline (BPG): BPGs are systematically developed, evidence-based documents that include recommendations for nurses and the interprofessional health team, educators, leaders, policy-makers, and persons and their families on specific clinical and healthy work environment topics. BPGs promote consistency and excellence in clinical care, health policies and health education, ultimately leading to optimal health outcomes for people, communities and the health system (122).

BPG Order Set™: Provides clear, concise and actionable intervention statements derived from a practice recommendation. BPG Order Sets™ can be readily embedded within electronic records, but they also may be used in paper-based or hybrid environments.

Burnout: "Exhaustion of physical or emotional strength or motivation, usually as a result of prolonged stress or frustration" (123).

Care coordination: "Deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care" (124).

CERQual criteria: When using CERQual, four components contribute to the assessment of confidence in the evidence for each individual finding:

1. Methodological limitations, which look at issues in the design of the primary study or problems in the way it was conducted.
2. Relevance, whereby all primary studies that support a finding are assessed together and a decision is made regarding the applicability of the findings to the population, phenomenon and setting outlined in the research question.
3. Coherence, whereby an assessment is made of whether the primary studies provide sufficient data and a convincing explanation for the review findings.
4. Adequacy of data, whereby an overall assessment is made about the richness and quantity of data that supports the review finding and phenomenon of interest (125).

Compassion fatigue: "Physical and mental exhaustion and emotional withdrawal experienced by those that care for sick or traumatized people over an extended period of time" (26).

Confidence in the Evidence from Reviews of Qualitative Research (CERQual): The Confidence in the Evidence from Reviews of Qualitative Research (CERQual) is a methodological approach for assessing the amount of confidence that can be placed in findings from a body of qualitative evidence about an outcome of interest. The assessment provides a transparent means to decide if the review finding reasonably represents the phenomenon under study, which can help expert panels make health recommendations (125).

Confounding variable: "Variables that have the potential to affect the outcome of a study, which are recognized before the study is initiated but that cannot be controlled, or variables not recognized until the study is in process" (126).

Consensus: A process used to reach agreement among a group or expert panel during a Delphi or modified Delphi technique (127). A consensus of 70 per cent agreement from all voting expert panel members was required to determine the direction and strength of the recommendations within this BPG.

Control: Rules implemented by a researcher to decrease the likelihood of error in a research study and to increase the probability that findings are a true representation of reality. A *control group* within a research study refers to a group of elements or subjects that are not exposed to an experimental treatment or intervention (126).

Cultural need: Anything required by and important to persons and families who are receiving palliative care that is related to their culture, values, beliefs, norms and ways of life (128). To provide culturally appropriate palliative and end-of-life care, the meaning of death and dying from the person's cultural perspective must be explored, including asking persons and families what that means to them, what is important to them, and what services, space and supports they require. Cultural needs can be related to information about diagnosis and prognosis, food and refreshments, pain management, medical practices, end-of-life rituals, and post-death rituals and procedures (129).

See *cultural safety* and *culture.*

Cultural safety: An environment that is physically, spiritually, socially and emotionally safe for people, where there is no assault, challenge or denial of their identity or what they need. It is about shared respect (130).

Culturally safe practices recognize and respect the cultural identities of others, and they safely meet their needs, expectations and rights (131).

See *cultural need* and *culture*.

Culture: Within this BPG, culture is broadly defined as the shared and learned values, beliefs, norms and ways of life of an individual or a group. Culture influences thinking, decisions and actions (128).

See *cultural need* and *cultural safety*.

Debriefing: Following an event or incident, debriefing involves obtaining emotional support from colleagues, followed by learning from the experience. The goal is to promote recovery, mitigate stress-related responses and prevent negative long-term effects. Debriefing should be a peer-driven approach (132). Debriefing can be both formal and informal.

Formal debriefing: Formal debriefing includes guidance from an individual trained in providing psychological support (132).

Informal debriefing: Informal debriefing includes emotional support from colleagues or any guidance offered by those who are not professionally trained or experienced in mental health (132).

Downgrade: When limitations in individual studies potentially bias the results in GRADE and GRADE–CERQual, the quality of evidence will decrease or be downgraded (133). For example, a body of quantitative evidence for one priority outcome may begin with high certainty, but due to serious limitations in one or more of the five GRADE criteria, it will be rated down one or two levels (134).

Education: Refers to obtaining theoretical knowledge and cultivating the ability to use critical thinking and decision-making skills. Education includes three continuous and fluid levels: awareness, training for specific needs and competency-based skills, and specialization (135). Education should be tailored to the scope of practice of the health provider and their role within the organization.

Education statement: Organizational approaches to the delivery of education in health-service organizations and academic institutions to support evidence-based practice. Education statements are based on an analysis of educational recommendations across several BPGs on diverse clinical topics and populations. Education statements can be applicable to all clinical BPGs and can be contextually adapted within health-service organizations and academic institutions to support implementation of clinical recommendations.

Effect (treatment effect): Best estimate of the outcomes related to the use of a treatment or intervention (136).

Emotion: "Complex reaction pattern, involving experiential, behavioral, and physiological elements, by which an individual attempts to deal with a personally significant matter or event" (137).

End of life: Persons are "approaching the end of life when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life threatening acute conditions caused by sudden catastrophic events" (138).

End-of-life care: are for persons who are expected to die in the foreseeable future and their families. It includes helping persons and families prepare for death, ensuring comfort and supporting decision making in a manner consistent with the person's prognosis and goals of care (3).

Estimate of effect: "A statistical measure indicating the magnitude of a treatment effect" (139).

Evidence-based nursing practice: The integration of the methodologically strongest research evidence with clinical expertise and patient values; unifies research evidence with clinical expertise and encourages the inclusion of patient preferences (140).

Evidence-to-Decision (EtD) Framework: A table that facilitates expert panels to make decisions when moving from evidence to recommendations. The purpose of the framework is to summarize the research evidence, outline important factors that can determine the recommendation, inform expert panel members about the benefits and harms of each intervention considered, and increase transparency about the decision-making process in the development of recommendations (11).

Existential: "The existential domain includes concerns regarding death (existential obliteration), freedom (the absence of external structure), isolation (the final unbridgeable gap separating self from all else), and the question of meaning (the dilemma of meaning-seeking creatures who recognize the possibility of a cosmos without meaning)" (141).

Expectations: Expectations as they relate to the plan of care are issues, hopes and fears identified by the person and/or family that require attention (3).

Family: "Those closest to the patient in knowledge, care and affection. The person defines his or her 'family' and who will be involved in his/her care and/or present at the bedside. May include:

- the biological family
- the family of acquisition (related by marriage/contract)
- the family of choice and friends (including pets)" (3).

Family caregiver: "Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care" (8). The term may be used interchangeably with *caregiver, carer, informal caregiver* and *primary caregiver*.

Goals of care: "A goals of care discussion between a patient (or his/her Substitute Decision Maker if the patient lacks capacity) and [health provider(s)] addresses the patient's goals for his or her care in the context of health-care consent and decision-making in advanced illness. The purpose of these discussions is to outline the patient's values, beliefs, wishes, perception of quality of life and what he or she characterizes as meaningful and important. Other elements include the patient's understanding of current health conditions, prognosis, and likely course of events if his or her goals of care are applied to potential treatment decisions. The goals of care discussion provides the foundation for decision-making and will often include the development of (and obtaining informed consent to) a plan of treatment" (3).

Gold Standards Framework (GSF): "The National Gold Standards Framework (GSF) Centre in End of Life Care is the national [UK] training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life. GSF improves the quality, coordination and organisation of care leading to better patient outcomes in line with their needs and preferences and greater cost efficiency through reducing hospitalisation" (142).

GRADE Criteria for observational studies: When using GRADE to assess the body of evidence for observational studies, in addition to the five criteria in "*GRADE Criteria for Randomized Controlled Trials*" three criteria assessed are:

1. Magnitude of effect, where magnitude of effect of an intervention on the outcome is assessed.
2. Dose-response gradient, where consideration is made regarding the effect of the intervention on the outcome.
3. Effect of plausible confounding, where consideration is made regarding residual confounders that cause an underestimation of treatment effect (11).

GRADE Criteria for randomized controlled trials: When using GRADE to assess the body of evidence for randomized controlled trials, five components contribute to the assessment of confidence in the evidence for each outcome:

1. Risk of bias, which focuses on the flaws in the design of a study or problems in its execution.
2. Inconsistency, which looks at a body of evidence and assesses whether the results point in the same direction, or if they are different.
3. Imprecision, which refers to the accuracy of results based on the number of participants and/or events included and the width of the confidence intervals across a body of evidence.
4. Indirectness, whereby each primary study that supports an outcome is assessed and a decision is made regarding the applicability of the findings to the population, intervention and outcome outlined in the research question.
5. Publication bias, where a decision is made about whether the body of published literature for an outcome potentially includes only positive or statistically significant results (11).

Grading of Recommendations Assessment, Development and Evaluation (GRADE): The Grading of Recommendations Assessment, Development and Evaluation (GRADE) is a methodological approach to assess the quality of a body of evidence in a consistent and transparent way, and to develop recommendations in a systematic manner. The body of evidence for an important and/or critical outcome is evaluated based on risk of bias, consistency of results, relevance of the studies, precision of the estimates and publication bias (11).

Grief: "A normal reaction to the loss of a loved one. It can also be a reaction to the loss of relationships, physical ability, opportunities or future hopes and dreams" (121).

Health provider: "A formal caregiver who is a member of an organization and accountable to norms of conduct and standards of practice. They may be professionals, support workers or volunteers" (6). *Health provider* refers to both regulated workers (e.g., nurses, physicians, dieticians or social workers) and unregulated workers (e.g., personal support workers) who are part of the interprofessional health team.

Regulated health provider: In Ontario, the Regulated Health Professional Act (RHPA), 1991, provides a framework for regulating 23 health professions, outlining the scope of practice and profession-specific controlled or authorized acts that each regulated professional is authorized to perform when providing health care and services (6).

Unregulated care provider: Unregulated health providers fulfill a variety of roles in areas that are not subject to the RHPA. They are accountable to their employers but not to an external regulating professional body (e.g., the College of Nurses of Ontario). Unregulated health providers fulfill a variety of roles and perform tasks that are determined by their employer and employment setting. Unregulated health providers only have the authority to perform a controlled act as set out in the RHPA if the procedure falls under one of the exemptions set out in the Act (7).

Home: Home refers to a physical house or other dwelling, such as long-term care, a hospice or other community setting. In palliative care, home impacts the person and their family's ways of experiencing, feeling or acting. It is something people have feelings for—a part of their personal identity, a location with complex and relational spatial connections, a site for care, a passive background and an absolute space—and it is constantly changing over time (143). For Indigenous persons, home may also refer to the final destination in their spiritual journey.

Interprofessional health team: "A team comprised of multiple health providers (regulated and unregulated) who work collaboratively to deliver comprehensive and quality health care and services to people within, between, and across health-care settings" (144). In palliative care and end-of-life care, interprofessional health teams include patients, family members, volunteers and caregivers, along with regulated and unregulated health providers.

See *interprofessional model of care.*

Interprofessional model of care: Refers to "teams with different health-care disciplines working together towards common goals to meet the needs of a patient population. Team members divide the work based on their scope of practice; they share information to support one another's work and coordinate processes and interventions to provide a number of services and programs" (8).

See *interprofessional health team.*

Medical Assistance in Dying (MAiD): While there is an intersection between MAiD and palliative care, and each may be part of the person's care path, "in accordance with federal legislation, MAiD [specifically] includes circumstances where a medical practitioner or nurse practitioner, at an individual's request: (a) administers a substance that causes an individual's death; or (b) prescribes a substance for an individual to self-administer to cause their own death" (145).

Meta-analysis: A systematic review of randomized controlled trials that uses statistical methods to analyze and summarize the results of the included studies (146).

See *systematic review.*

Nurse: "Refers to registered nurses, licensed practical nurses (referred to as registered practical nurses in Ontario), registered psychiatric nurses and nurses in advanced practice roles such as nurse practitioners and clinical nurse specialists" (144).

Nurse-led care: Nurse-led care refers to "a continuum with, at one end, nurses undertaking highly protocol driven, focused tasks and, at the other end, responding to far more diverse challenges in terms of clinical decision making" (147).

Outcomes: A dependent variable or the clinical and/or functional status of a patient, provider or population that is used to assess if an intervention is successful. In GRADE, outcomes are prioritized based on if they are critical for decision making, important but not critical for decision making or not important. This helps the literature search and systematic reviews to be more focused (11).

Palliative care: A philosophy of—and approach to—care. Palliative care aims to improve the quality of life of persons and their families facing life-limiting illness by preventing and relieving suffering through early identification, assessment and treatment of symptoms (9). Also referred to as *hospice palliative care*.

Principles of palliative care include the following:

- Relieve suffering and improve the quality of living and dying.
- Address the physical, psychological, social, spiritual (existential) and practical issues of persons and their families, and their associated expectations, needs, hopes and fears.
- Prepare persons and their families for self-determined life closure and the dying process and help them manage it.
- Helps families cope with loss and grief during the illness and bereavement experience.
- Treat all active issues, prevent new issues from occurring and promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization (10).

Person: In the context of this Guideline, "person" refers to those experiencing the last 12 months of progressive life-limiting illness. The term is used interchangeably with *patient*, *resident* and other terms found in the literature.

PICO research question: A framework to outline a focused question. It specifies four components:

1. The patient or population being studied.
2. The intervention to be investigated.
3. The alternative or comparison intervention.
4. The outcome that is of interest (11).

Plan of care: The plan of care is individualized and person-centred. It reflects the wishes, goals and values of the person in the last 12 months of life and their family.

Preference: The power or opportunity of choosing (148).

Qualitative research: An approach to research that seeks to convey how human behaviour and experiences can be explained within the context of social structures using an interactive and subjective approach to investigate and describe phenomena (149).

Quasi-experimental study: A study that estimates causal effects by observing the exposure of interest, but in which the experiments are not directly controlled by the researcher and lack randomization (e.g., before-and-after designs) (150).

Randomized controlled trial (RCT): An experiment in which the investigator assigns one or more interventions to participants who are randomly allocated to either the experimental group (receives intervention) and the comparison (conventional treatment) or control group (no intervention or placebo) (146).

Recommendation: A course of suggested action(s) that directly answer a recommendation question. A recommendation is based on a systematic review of the literature and is made in consideration of its potential benefits and harms, values and preferences from a person-centered perspective, and its impact on health equity. All recommendations are given a strength—either **strong** or **conditional**—through expert panel consensus. It is important to note that recommendations should not be viewed as prescriptive, as recommendations cannot take into account all of the unique features of individual, organizational and clinical circumstances (11).

A **strong recommendation** "…reflects the expert panel's confidence that the desirable effects of an intervention outweigh its undesirable effects (strong recommendation *for* an intervention) or that the undesirable effects of an intervention outweigh its desirable effects (strong recommendation *against* an intervention)" (11). A strong recommendation implies that the majority of persons will be best serviced by the recommended action (11).

A **conditional recommendation** reflects the expert panel's confidence that while some uncertainty exists, the desirable effects probably outweigh the undesirable effects (i.e., conditional recommendation *for* an intervention) or that the undesirable effects probably outweigh the desirable effects (i.e., a conditional recommendation *against* an intervention) (11). A conditional recommendation implies that not all persons will be best served by the recommended action, and that there is a need for more careful consideration of personal circumstances, preferences and values (11).

Relational coordination: Includes shared goals, shared knowledge and mutual respect, supported by clear, timely and effective communication within an organization (151).

Resilience: A person's ability to thrive in the face of stress and traumatic experiences (33).

Scoping review: "Scoping reviews have been described as a process of mapping the existing literature or evidence base. Scoping reviews can be used in a number of ways, for example identifying research gaps and summarizing findings of research. They can also be used to inform systematic reviews" (152).

Secondary traumatic stress: "The natural, consequent behaviors and emotions resulting from knowledge about a traumatizing event experienced by a significant other. It is the stress resulting from helping or wanting to help a traumatized or suffering person" (153).

See *compassion fatigue*.

Self-regulation: "The control of one's behavior through the use of self-monitoring (keeping a record of behavior), self-evaluation (assessing the information obtained during self-monitoring), and self-reinforcement (rewarding oneself for appropriate behavior or for attaining a goal)" (154).

Setting of care: The location where care is provided. Settings of care may include: the person's home; primary care settings (e.g., a doctor's office or community clinic); acute, chronic or long-term care facilities; hospice or palliative care units; jails or prisons; or (for persons with no home) the street or homeless shelters (3).

Shared decision-making: This approach to making decisions is based on an acknowledgement of each person's individual autonomy and right to self-determination (i.e., the freedom to make one's own decisions and control one's life). It relies on information from two experts: the health provider (the expert on evidence-based practices) and the person making the decisions for their health. The person is the expert on themselves (e.g., their beliefs, culture, spirituality and values), their experience of health and their life circumstances (i.e., their social world and lived experiences with health). Together, these experts share and discuss the best options for health and services so the person can make a decision and choose the best option for them (155–157).

Social determinants of health: "The conditions in which people are born, grow, live, work and age, and the systems put in place to deal with illness" (158).

Spirituality: "Dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred." Spirituality is multidimensional and considers existential challenges, value-based considerations and attitudes, and religious considerations and foundations (159).

Stakeholder: An individual, group or organization that has a vested interest in the decisions and actions of organizations, and that may attempt to influence decisions and actions (160). Stakeholders include all of the individuals and groups directly or indirectly affected by the change or solution to the problem.

Structurally vulnerable populations: "...people living in poverty and who are experiencing some level of homelessness, while at the same time are also experiencing various forms of racism, a history of or ongoing trauma and violence, social isolation, stigma associated with mental health issues, cognitive impairments, behavioural issues, substance use (previous or ongoing), interactions with the criminal justice system, and mobility issues and/or disability (186).

Substitute decision-maker: "Person(s) who provides or refuses consent for treatment or to withdraw treatment on behalf of another person when that person is mentally incapable of making his or her decisions about treatment. The substitute decision-maker is required to make decisions on a person's behalf following any wishes expressed about care when mentally capable. If the substitute decision-maker does not know any wishes applicable to the treatment decision to be made, he or she is required to act in the person's best interests" (161).

"A substitute decision-maker can be chosen in several different ways.

- By the person: The person can appoint someone to be their substitute decision-maker in a "Power of Attorney for Personal Care." More than one substitute decision-maker may be appointed.
- Automatically under the Ontario's Health Care Consent Act: If a substitute decision-maker is not appointed, the person who will make decisions on the person's behalf will be chosen based on the ranked list set out in Ontario's Health Care Consent Act.
- By the court: If a person has a court-appointed guardian, then that person automatically becomes their substitute decision-maker.
- By the Ontario Consent and Capacity Board: If the person is not mentally capable of making decisions, one of their family or friends can apply to the Consent and Capacity Board to be named as their "representative," which is a type of substitute decision-maker. However, if the person prepared a valid Power of Attorney for Personal Care, the Consent and Capacity Board will not appoint anyone else.
- By the government: If there is no other person capable, available or willing to give or refuse consent for treatment or to withdraw treatment on the person's behalf, the government will appoint the Public Trustee and Guardian to be the decision-maker of last resort for the person" (161).

Surrogate outcome: A surrogate outcome is a substitute measure to the one originally selected. Surrogate outcomes are considered when evidence about the desired outcomes is lacking or unexplored (11).

Systematic reviews: A comprehensive review of the literature that uses clearly formulated questions and systematic and explicit methods to identify, select and critically appraise relevant research. A systematic review collects and analyzes data from the included studies and presents them, sometimes using statistical methods (146).

See *meta-analysis*.

Value: "A moral, social, or aesthetic principle accepted by an individual or society as a guide to what is good, desirable, or important" (162).

Wish: A person's will or desire (163).

Appendix B: RNAO Guidelines and Resources that Align with this Guideline

The following are topics that align with this guideline, with suggested BPGs and resources from other organizations.

TOPIC	RESOURCE(S)
Care transitions	Registered Nurses' Association of Ontario (RNAO). Care transitions. Toronto (ON): RNAO; 2014. Available from: RNAO.ca/sites/rnao-ca/files/Care_Transitions_BPG.pdf (English) RNAO.ca/sites/rnao-ca/files/TransitionsDesSoins-RNAO.pdf (French)
Constipation	Registered Nurses' Association of Ontario (RNAO). Prevention of constipation in the older adult population. Toronto (ON): RNAO; 2005. Available from: RNAO.ca/bpg/guidelines/prevention-constipation-older-adult-population (English) RNAO.ca/bpg/translations/pr%C3%A9vention-de-la-constipation-chez-les-personnes-%C3%A2g%C3%A9es (French)
Crisis intervention	Registered Nurses' Association of Ontario (RNAO). Crisis intervention for adults using a trauma-informed approach: initial four weeks of management. 3rd ed. Toronto (ON): RNAO; 2018. Available from: RNAO.ca/bpg/guidelines/crisis-intervention
Delirium, dementia and depression	Registered Nurses' Association of Ontario (RNAO). Delirium, dementia and depression in older adults: assessment and care. Toronto (ON): RNAO; 2010. Available from: RNAO.ca/sites/rnao-ca/files/3Ds_BPG_WEB_FINAL.pdf
End-of-life care in the last days and hours	Registered Nurses Association of Ontario (RNAO). End-of-life care during the last days and hours. Toronto (ON): RNAO; 2011. Available from: RNAO.ca/sites/rnao-ca/files/End-of-Life_Care_During_the_Last_Days_and_Hours_0.pdf

TOPIC	RESOURCE(S)
Implementation science, implementation frameworks and resources	Active Implementation Hub. In: National Implementation Research Network [Internet]. [place unknown]: State Implementation and Scaling-up of Evidence-based Practices Center (SISEP); [date unknown]. Co-published by they National Implementation Research Centre. Available from: http://implementation.fpg.unc.edu
	Canadian Patient Safety Institute. Improvement frameworks: getting started kit [Internet]. [place unknown]: Safer Healthcare Now!; 2015. Available from: http://www.patientsafetyinstitute.ca/en/toolsResources/ImprovementFramework/Documents/Improvement%20Frameworks%20GSK%20EN.PDF (English) http://www.patientsafetyinstitute.ca/fr/toolsresources/ImprovementFramework/Documents/Improvement%20Frameworks%20GSK%20FR.pdf (French)
	Registered Nurses' Association of Ontario (RNAO). Toolkit: implementation of best practice guidelines. 2nd ed. Toronto (ON): RNAO; 2012. Available from: RNAO.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition (English) RNAO.ca/sites/rnao-ca/files/Toolkit_2ed_French_with_App.E.pdf (French)
	Seminal publications [Internet]. [place unknown]: Dissemination & Implementation Models in Health Research & Practice; [date unknown]. Available from: http://dissemination-implementation.org/content/resources.aspx
Interprofessional collaboration	Registered Nurses' Association of Ontario (RNAO). Developing and sustaining interprofessional health care: optimizing patients/clients, organizational, and system outcomes. Toronto (ON): RNAO; 2013. Available from: RNAO.ca/sites/rnao-ca/files/DevelopingAndSustainingBPG.pdf (English) RNAO.ca/bpg/language/d%C3%A9veloppement-et-maintien-des-soins-de-sant%C3%A9-interprofessionnels-optimisation-des-r%C3%A9sul (French)
Oral health	Registered Nurses' Association of Ontario (RNAO). Oral health: supporting adults who require assistance. 2nd ed. Toronto (ON): RNAO; 2020. Available from: https://rnao.ca/bpg/guidelines/oral-health-supporting-adults-who-require-assistance-second-edition

TOPIC	RESOURCE(S)
Pain	Registered Nurses' Association of Ontario (RNAO). Assessment and management of pain. 3rd ed. Toronto (ON): RNAO; 2013. Available from: RNAO.ca/bpg/guidelines/assessment-and-management-pain (English) RNAO.ca/bpg/translations/%C3%A9valuation-et-prise-en-charge-de-la-douleur (French)
Person- and family-centred care	Registered Nurses' Association of Ontario (RNAO). Person- and family-centred care. Toronto (ON): RNAO; 2015. Available from: RNAO.ca/bpg/guidelines/person-and-family-centred-care (English) RNAO.ca/bpg/language/soins-ax%C3%A9s-sur-les-besoins-de-la-personne-et-de-la-famille (French)
Pressure injuries	Registered Nurses' Association of Ontario (RNAO). Assessment and management of pressure injuries for the interprofessional team. 3rd ed. Toronto (ON): RNAO; 2016. Available from: RNAO.ca/bpg/guidelines/pressure-injuries (English) RNAO.ca/bpg/language/l%C3%A9sions-de-pression (French)
Social determinants of health	Registered Nurses' Association of Ontario (RNAO). Social determinants of health. Toronto (ON): RNAO; 2013. Available from: RNAO.ca/sites/rnao-ca/files/rnao_sdh_brochure_2013.pdf

Appendix C: Education Statements

Education Statements for This Guideline

RNAO has been at the forefront of creating BPGs since 1999; its first BPG was issued in 2002. From the outset, RNAO recognized the importance that individual and organizational approaches to the delivery of education had on clinical BPG content that had been developed to support evidence-based practice change. As such, RNAO clinical BPGs have included education recommendations directed to those responsible for the academic and in-service education of nursing students, nurses and the interprofessional health team. These recommendations have outlined core content and training strategies required for entry-level health programs, continued education and professional development.

An in-depth analysis of RNAO's educational recommendations was conducted in 2018. It included clinical BPGs published within a five-year time frame, as all clinical BPGs published within this period are based on a systematic review of the literature. It examined 26 education recommendations from nine different BPGs with diverse clinical topics and populations.

A rigorous thematic analysis showed similarities across BPGs. Thus, it was deemed appropriate to create standard education statements that would be applicable to all clinical BPGs to support evidence-based practice changes. The resulting education statements and associated discussion of the literature are described below. These statements can be contextually adapted within health-service organizations and academic institutions to support the implementation of clinical recommendations for various BPG topic areas.

EDUCATION STATEMENT 1:

ACADEMIC INSTITUTIONS INTEGRATE EVIDENCE-BASED GUIDELINES INTO CURRICULA FOR PRE- AND POST-LICENSURE NURSES AND OTHER REGULATED HEALTH PROVIDERS.

Discussion of Literature:

The thematic analysis of the education recommendations described above, found the theme of: "academic institutions integrate evidence-based guidelines into curricula for pre- and post-licensure nurses and other regulated health providers," as foundational to evidence-based practice capacity building. The following BPGs were analyzed:

- *Assessment and Management of Pain, Third Edition* (2013)
- *Care Transitions* (2014)
- *Delirium, Dementia, and Depression in Older Adults: Assessment and Care, Second Edition* (2016)
- *Engaging Clients Who Use Substances* (2015)
- *Person- and Family-centred Care* (2015)
- *Preventing and Addressing Abuse and Neglect of Older Adults: Person-centred, Collaborative, System-wide Approaches* (2014)
- *Primary Prevention of Childhood Obesity, Second Edition* (2014)
- *Working with Families to Promote Safe Sleep in Infants 0–12 Months of Age* (2014)

Academic institutions should consider integrating guideline content into theoretical and practice-based courses for nurses and other regulated health providers, including social workers, physiotherapists, occupational therapists, dieticians and pharmacists in pre-licensure and post-licensure programs. Pre-licensure education establishes foundational knowledge that can be strengthened and augmented, as necessary, within health-service organizations. Post-licensure education at the graduate level may include preparing nurses and other regulated health providers for advanced practice roles and functions within clinical practice, education, administration, research and policy (164). As such, the integration of guideline content into curricula will differ in terms of educational content and complexity, based on the overall educational objectives of the program. In both cases, integrating guideline content into curricula supports student learning that is consistent with evidence-based practices, with the ultimate goal of enhancing the health outcomes of persons and families.

To support the integration of evidence-based guidelines into curricula, the following approaches may be utilized: (1) developing multi-level guideline-related learning objectives; and (2) designing guideline-related teaching and learning strategies (165). Both approaches are outlined below.

1. **Developing multi-level guideline-related learning objectives:** Guideline-related learning objectives at multiple levels of a program (pre-licensure and post-licensure) facilitate integration of guideline content into curricula.
   - At the program level, such integration broadens student knowledge, attitude, judgment and skills. For instance, a program-level outcome at the graduate level may include student awareness of elements of implementation science to support uptake and sustained use of guidelines in clinical settings (165).
   - At the course level, integration of guideline content supports student learning that is consistent with evidence-based practices within academic and practice settings. For example, course-level outcomes at the undergraduate level may include students being able to gain increased knowledge about guidelines, select guidelines relevant to practice (and provide rationale for their selection) and integrate guideline recommendations into plans of care for persons and families (165).

2. **Designing guideline-related teaching and learning strategies:** Teaching strategies should be tailored to address the program-level educational objectives and needs of learners, and to equip the learner to improve practice and promote positive outcomes (166). The various guideline-related teaching and learning strategies are outlined below.
   - **Access to BPG-related resources:** Educators can promote and facilitate access to BPG-related links and resources. For example, providing access to the RNAO Nursing Best Practice Guidelines App (see RNAO.ca/bpg/pda/app) enables students to access content from guidelines within classroom and practice settings (165).
   - **Assignments and tests:** Students may be asked to incorporate guidelines into their learning plans or to write a reflective journal related to a guideline important to their area of practice. Tests or exam questions that demonstrate critical thinking related to guidelines can also be used. Overall, guideline-related assignments and tests can assist students to reflect upon guidelines, understand their application and critique them (165).

- **Interactive classroom activities:** Interactive learning activities within the classroom setting can support students to obtain additional information, participate in problem-solving and articulate knowledge gained. Examples include: (i) assigning group work to help students learn how to navigate a guideline and become familiar with its recommendations; (ii) using case studies to provide students with opportunities to identify and apply guideline recommendations in care plans; and (iii) using videos and role playing to promote skills in articulating the rationale for selecting specific guidelines and recommendations in care plans (165).
- **Lectures:** Educators can use lectures as a means to provide a broad understanding of guidelines, specifically the rigorous process of guideline development and their various recommendations. Lectures can provide students with an understanding of the scope and strength of evidence that informs recommendations (165).
- **Pre- and post-clinical conference discussions:** Focusing on a guideline in pre- and post-clinical conference discussions can support the critical thinking of students when: (i) developing care plans; (ii) considering modifications based on guideline recommendations; (iii) articulating rationale for clinical decisions; and (iv) evaluating the outcome of interventions. Students have the opportunity to evaluate if policies and procedures within the practice setting align with best evidence, and they can identify potential areas for practice change and consider how to initiate change (165).
- **Preceptorship or mentorship in clinical placements:** Preceptors within clinical settings play an integral role in teaching practical skills that complement the theoretical learning of students. Preceptors are responsible for providing clinical teaching and supervision, and they perform formal student evaluation (168). Preceptors can support students to integrate guideline content into their learning objectives and clinical activities to promote evidence-based knowledge and practice.
- **Simulation:** High-quality digital simulation within skills lab settings can ease the uncertainty of students related to clinical practice; it can also increase skill acquisition, self-confidence and satisfaction. Faculty trained in pedagogy can use simulation to teach students content related to safe and effective person and family care within a standardized clinical environment (167). Educators can support students to incorporate guideline content into simulated practice sessions when teaching evidence-based practice (165).

EDUCATION STATEMENT 2:

Health service organizations use strategies to integrate evidence-based guidelines into education and training of nurses and other health providers.

Discussion of Literature:

The thematic analysis of the education recommendation statements in a number of BPGs found the second theme of "health-service organizations use strategies to integrate evidence-based guidelines into education and training of nurses and other health providers" as foundational to evidence-based practice capacity-building. The following BPGs were analyzed:

- *Assessment and Management of Pain, Third Edition* (2013)
- *Care Transitions* (2014)
- *Delirium, Dementia, and Depression in Older Adults: Assessment and Care, Second Edition* (2016)
- *Engaging Clients Who Use Substances* (2015)
- *Person- and Family-centred Care* (2015)
- *Preventing and Addressing Abuse and Neglect of Older Adults: Person-centred, Collaborative, System-wide Approaches* (2014)
- *Primary Prevention of Childhood Obesity, Second Edition* (2014)
- *Working with Families to Promote Safe Sleep in Infants 0–12 Months of Age* (2014)

Nurses and other health providers should continually seek new knowledge, identify opportunities for professional growth and pursue ongoing learning throughout their careers. Participation in education and training ensures congruence with evidence-based practices, enhances competence and improves care quality and individual outcomes (169). Integrating guideline content into education and training programs within health-service organizations can improve evidence-based knowledge and skills for post-licensure nurses and other health providers.

Education and training programs should be based on the principles of adult learning, including the following:

- Adults have an awareness of learning needs and goals.
- Adults are self-directed and autonomous.
- Adults value and utilize prior life experiences.
- Adults have a readiness to learn.
- Adults are motivated to learn.
- Adults are presented knowledge and skills in the context of practical, real-life situations (170).

Furthermore, education and training should be appropriate to the health provider's scope of practice and their defined role. Education and training strategies may include the following:

- **In-service education sessions:** In-service education sessions can be planned by clinical experts within practice settings to support the utilization of a specific guideline or recommendations stimulating evidence-based practice among staff. The education may include one-on-one or group sessions, and it should address the needs of learners. It is recommended that the education sessions are followed with refresher or booster sessions to provide feedback and enhance staff learning (171, 172).
- **Post-licensure mentorship:** Post-licensure mentorship involves providing new graduates or less experienced staff with guidance for skill development and support for growth of professional roles. Research suggests that working with mentors reduces stress and improves satisfaction for new staff during the transition process (176). Mentors can support integration of guideline content while teaching evidence-based practice.
- **Quality improvement:** Participating in quality improvement within workplace settings can support nurses and health workers to recognize sentinel events and examine ways to improve care. Meeting accreditation standards is an important quality improvement activity that bridges gaps between current and best practices and supports continued competence. Examples of strategies that nurses and other health providers can use to meet accreditation standards include the following:
  - Participating in a unit-based guideline implementation process to promote patient safety, reduce risks and improve care outcomes.
  - Choosing guideline-specific recommendations to facilitate practice change.
  - Sharing knowledge and lessons learned from reviewing guidelines with the accreditation committee (174, 175).

  Other quality improvement opportunities include participating in incident reporting, patient safety initiatives and other health initiatives within areas of practice.
- **Workshops/seminars:** Highly interactive workshops and seminars help nurses and health providers maintain evidence-based best practice when they incorporate a variety of teaching–learning strategies, including pre-circulated materials, small group discussions using case studies, and multimedia such as Power Point and videos that integrate relevant guidelines and recommendations. RNAO's Best Practice Champions Workshop and BPG Learning Institutes are examples of programs that provide education on how to implement BPGs within practice settings (173).

EVALUATION

All educational strategies require evaluation to monitor the adoption of knowledge and measure the impact on clinical outcomes. RNAO has developed the *Educator's Resource: Integration of Best Practice Guidelines* (2005) to provide strategies for educators within academia and practice settings to introduce BPGs to student nurses, faculty, nurses and other health providers. The resource provides guidance on student evaluation strategies that include self-evaluation, peer-evaluation and end-of-course evaluations by the educator.

Furthermore, RNAO has developed the *Practice Education in Nursing* (2016) BPG to provide evidence-based recommendations that support the application of knowledge by student nurses to various practice settings. The guideline also assists nurses, nurse educators, preceptors and other members of the interprofessional health team to understand the effective use of teaching–learning strategies in clinical settings.

The RNAO *Toolkit: Implementation of Best Practice Guidelines* (2012)* identifies the following strategies for evaluation of provider practice change and health outcomes for persons within health-service organizations:

- Pre- and post-tests for staff educational sessions.
- Staff focus groups/interviews.
- Observation of patient–provider encounters.
- Chart audits to determine the impact on person and family outcomes.
- Person and family satisfaction surveys or interviews.

* The RNAO *Toolkit: Implementation of Best Practice Guidelines* (2012) is under review. The next edition is expected to be issued in 2021.

Appendix D: Guideline Development Methods

This appendix presents an overview of the RNAO guideline development process and methods. RNAO is unwavering in its commitment that every BPG be based on the best available evidence. The Grading of Recommendations Assessment, Development and Evaluation (GRADE) and Confidence in the Evidence from Reviews of Qualitative Research (CERQual) methods have been implemented to provide a rigorous framework and meet international standards for guideline development.

Scoping the Guideline

The scope sets out what an RNAO BPG will and will not cover (see **Purpose and Scope**). To determine the scope of this BPG, the RNAO Best Practice Guideline Development and Research Team conducted the following steps.

1. Reviewed the RNAO BPG End-of-life Care During the Last Days and Hours (2011) to understand its purpose, scope and recommendations.
2. Conducted a guideline search and gap analysis. The RNAO Best Practice Guideline Development and Research Team searched an established list of websites for guidelines and other relevant content published between January 2011 and April 2017. The purpose of the guideline search and gap analysis was to gain an understanding of existing guidelines regarding end-of-life care in order to identify opportunities for addressing the purpose and scope of this BPG. The resulting list was compiled based on knowledge of evidence-based practice websites and recommendations from the literature. The RNAO expert panel members were asked to suggest additional guidelines (see **Figure 5** in **Appendix E**). Detailed information about the search strategy for existing guidelines, including the list of websites searched and the inclusion criteria used, is available at RNAO.ca/bpg/guidelines/palliative-approach-care-last-12-months-life.

   The guidelines were reviewed for content, applicability to nursing scope of practice, accessibility and quality. Two guideline development methodologists appraised six international guidelines using the Appraisal of Guidelines for Research Evaluation Instrument II (AGREE II) tool and came to consensus on an overall score for each guideline (177). Guidelines with a score of 6 or 7 (on a 7-point Likert scale) were considered to be of high quality. The systematic reviews that answered research questions in high-quality guidelines were considered to be beyond the scope of this BPG.

   The following guidelines were appraised as follows:

   - BC Cancer Agency. Palliative care for the patient with incurable cancer or advanced disease—part 2: pain and symptom management. Victoria (BC): Guidelines and Protocols Advisory Committee; 22 Feb 2017. Available from: https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-pain-management
     - Score: 3 out of 7. This guideline was used as a supporting resource in this BPG.
   - BC Cancer Agency. Palliative care for the patient with incurable cancer or advanced disease—part 3: grief and bereavement. Victoria (BC): Guidelines and Protocols Advisory Committee; 22 Feb 2017. Available from: https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-grief-and-bereavement
     - Score: 3 out of 7. This guideline was used as a supporting resource in this BPG.
   - Ontario Health Technology Advisory Committee (OHTAC). End-of-life health care in Ontario: OHTAC recommendation. Toronto (ON): Queen's Printer for Ontario; 2014. Available from: http://www.hqontario.ca/Portals/0/Documents/evidence/reports/recommendation-eol-1411-en.pdf
     - Score: 4 out of 7. This guideline was used as a supporting resource in this BPG.

- McCusker M, Ceronsky L, Crone C, Epstein H, Greene B, Halvorson J et al. Palliative care for adults. [place unknown]: Institute for Clinical Systems Improvement; 2013. Available from: https://www.icsi.org/wp-content/uploads/2019/01/PalliativeCare.pdf
  - Score: 5 out of 7. This guideline was used as a supporting resource in this BPG.
- National Clinical Guidance Centre. Care of dying adults in the last days of life. London (UK): National Clinical Guidance Centre; 2015. Available from: https://www.nice.org.uk/guidance/ng31/evidence/full-guideline-pdf-2240610301
  - Score: 6 out of 7. This guideline was used as a supporting resource in this BPG and the research questions informing this guideline were considered out of scope for this BPG
- National Institute for Health and Care Excellence (NICE). Palliative care for adults: strong opioids for pain relief. London (UK): NICE; 2012. Available from: https://www.nice.org.uk/guidance/cg140
  - Score: 6 out of 7. This guideline was used as a supporting resource in this BPG and the research questions informing this guideline were considered out of scope for this BPG.

3. Performed a scoping review to determine the depth of peer-reviewed studies in the area of Medical Assistance in Dying (MAiD).
   - Suva G, Penney T, McPherson CJ. Medical assistance in dying: a scoping review to inform nurses' practice. J Hosp Palliat Nurs. 2019;21(1):46-53.
4. Undertook 24 key informant interviews with experts in the field, including direct care health providers, administrators, researchers, and family members and/or caregivers with lived experience.

Assembly of the Expert Panel

In alignment with the Organizational Statement on Diversity and Inclusivity that appears in its Mission and Values, RNAO aims for diversity in the membership of its expert panels (you can find a copy of the RNAO Mission and Values at RNAO.ca/about/mission). RNAO also works to include persons impacted by BPG recommendations, especially persons with lived experiences and caregivers, to be included as expert panel members.

RNAO finds and selects members of an expert panel through multiple methods, including: (a) searching the literature for researchers in the topic area; (b) soliciting recommendations from key informant interviews; (c) drawing from established professional networks (such as RNAO interest groups, the Champions Network© and BPSO©); (d) connecting with other nursing and health provider associations; (e) conferring with topic-relevant technical associations or organizations; and (f) speaking with advocacy bodies. When relevant, a call for an expression of interest from expert panel members who have previously served on prior editions of the BPG is completed.

For this BPG, the RNAO Best Practice Guideline Development and Research Team assembled a panel of experts from nursing practice, administration, research, education and policy, as well as other members of the interprofessional health team representing a range of sectors and practice areas, and persons with lived experience (see the **RNAO Best Practice Guideline Expert Panel**).

The expert panel engaged in the following activities:

- approved the scope of this BPG;
- determined the recommendation questions and outcomes to be addressed in this BPG;
- participated in a consensus development process to finalize recommendation statements;

- provided feedback on the draft of this BPG;
- participated in the development of evaluation indicators; and
- identified appropriate stakeholders to review the draft BPG prior to publication.

The expert panel co-chairs participated in the following activities:

- monthly co-chair meetings with the guideline development methodologist and guideline development project coordinator;
- facilitated expert panel meetings;
- provided in-depth guidance on clinical and/or research issues; and
- moderated and acted as tiebreakers in voting processes.

Conflict of Interest

In the context of RNAO best practice guideline development, the term "conflict of interest" (or COI) refers to situations in which an expert panel member's or RNAO staff member's financial, professional, intellectual, personal, organizational or other relationships may compromise their ability to independently conduct panel work. Declarations of COI that might be construed as constituting a perceived and/or actual conflict were made by all members of the RNAO expert panel prior to their participation in guideline development work using a standard form. Expert panel members also updated their COI at the beginning of each in-person guideline meeting.

Any COI declared by an expert panel member was reviewed by the RNAO Best Practice Guidelines Development and Research Team and expert panel co-chairs. No limiting conflicts were identified. See "Declarations of Conflicts of Interest Summary" at https://rnao.ca/bpg/guidelines/palliative-approach-care-last-12-months-life.

Identifying Priority Recommendation Questions and Outcomes

In March 2017, the RNAO Best Practice Guideline Development and Research Team and expert panel convened in-person to determine the purpose, scope and priority recommendation questions for this BPG. In the spring of 2017 the RNAO Best Practice Guideline Development and Research Team began to implement the GRADE and CERQual methodologies. As such, this BPG is considered a *transitional* GRADE BPG, in that the GRADE approach was adapted within the process of guideline development. In July 2017, the RNAO Best Practice Guideline Development and Research Team and the expert panel co-chairs modified the recommendation questions and outcomes in alignment with GRADE standards for assessing and presenting the evidence. The recommendation questions and priority outcomes were informed by the guideline gap analysis, the scoping review of the literature and discussion with the co-chairs.

Each recommendation question informed a PICO research question which guided the systematic reviews. The four recommendation questions and their respective PICO research questions are presented below:

Recommendation Question 1a: Should an interprofessional* approach be recommended for the provision of care to adults in the last 12 months of life?

PICO Research Question:
Population: Adults aged 18 years of age and older with life-limiting, progressive illness and their families.
Intervention: Interprofessional approach to care.
Comparison: Standard care or no comparator.
Outcomes: Access to care, coordination of care, transitions in care, person and family experiences, effectiveness of approach to care.

Recommendation Question 1b: Should an interprofessional* approach be recommended for the provision of care to adults in the last 12 months of life?

PICO Research Question:
Population: Nurses, in collaboration with the interprofessional health team.
Intervention: Interprofessional approach to care.
Comparison: Standard care or no comparator.
Outcome: Effectiveness of approach to care.

Recommendation Question 2: What nurse-led interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life?

PICO Research Question:
Population: Adults aged 18 years of age and older with life-limiting, progressive illness and their families.
Intervention: Nurse-led interventions.
Comparison: Standard care or no comparator.
Outcomes: Support for spiritual care, support for emotional care, support for existential care, fulfill/address person's expectations** (***surrogate outcome***[G]*: care in alignment with the person's wishes*), culturally safe care, place of death.

Recommendation Question 3: Should (a) continuing education, (b) debriefing and (c) targeted skills training be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families?

PICO Research Question:
Population: Nurses, in collaboration with the interprofessional health team.
Intervention: (a) Continuing education regarding personal responses to stress, self-care and psychological techniques; (b) debriefing by staff skilled in providing psychological support; and (c) targeted skills training to develop personal control measures.
Comparison: Standard care or no comparator.
Outcomes: Compassion fatigue, moral distress** (*surrogate outcome: distress/stress*), resilience.

* The original intervention in Recommendation Question 1a and 1b explored a transdisciplinary approach; however, after completing literature searches, title and abstract screening, and a full-text relevance review, no literature was identified that answered the recommendation question. In consultation with the co-chairs, a proxy intervention—interprofessional care—was chosen as an alternative intervention.

** The outcomes—person's expectations and moral distress—were not found in the literature. As a result, care in alignment with the person's wishes and stress/distress were respectively chosen as surrogate outcomes after consultation with expert panel co-chairs.

Systematic Retrieval of the Evidence

RNAO BPGs are based on a comprehensive and systematic review of the literature.

For this BPG, a search strategy was developed by RNAO's Best Practice Guideline Development and Research Team and a health sciences librarian for each of the PICO research questions. A search for relevant research studies published in English between January 2012 and December 2017 was applied to the following databases: Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE, Medline In-Process/E-Pub, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, PsycINFO and Embase. Expert panel members were asked to review their personal libraries for key studies not found through the above search strategies. Detailed information on the search strategy for the systematic reviews, including the inclusion and exclusion criteria and search terms, is available at RNAO.ca/bpg/guidelines/palliative-approach-care-last-12-months-life.

Studies were independently assessed for relevance and eligibility by the inclusion and exclusion criteria. Any disagreements were resolved through consensus.

All included articles were independently assessed for risk of bias by study design using validated and reliable tools. Randomized controlled trials were assessed using the Risk of Bias 2.0 tool (178), **quasi-experimental studies**[G] and observational studies were assessed using the ROBINS-I tool (179), systematic reviews were assessed using the AMSTAR 2 tool (180), and qualitative studies were assessed using an adapted version of the Critical Appraisal Skills Program (CASP) qualitative checklist (181). One masters-prepared guideline development methodologist assessed risk of bias and a PhD-prepared research director reviewed and validated the assessments. Disagreements between reviewers were resolved through consensus discussion.

Data extraction was performed simultaneously. One masters-prepared guideline development methodologist performed data extraction, and a PhD-prepared research director reviewed and cross-checked for accuracy. In total, 53 studies were included across all three systematic reviews (see **Figures 6**, **7** and **8** in **Appendix E**).

Following completion of the systematic reviews, an updated literature search for studies published in 2018 and 2019 was completed to supplement content within the Values and Preferences, Health Equity and Practice Notes sections of the Discussion of Evidence for each recommendation statement. The search was completed by a health sciences librarian within the following databases: CINAHL, MEDLINE, Medline In-Process/E-Pub, EMBASE and PsycINFO. A total of 10 articles were included from the 2018 updated literature search, and an additional four articles were included from the 2019 updated literature search. Findings were incorporated into the Discussion of Evidence of Recommendations 1.1, 1.2, 2.1, 2.2, 2.3, 2.4, 2.6, 3.1 and 3.2.

Determining Certainty and Confidence of Evidence

Certainty of Evidence

The certainty of quantitative evidence (i.e., the extent to which one can be confident that an estimate of the effect is correct) is determined using GRADE methods (11). First, the certainty of the evidence is rated for each prioritized outcome across studies (i.e., for a body of evidence) per recommendation question (11). This process begins with the study design and then requires an examination of five criteria—risk of bias, inconsistency, imprecision, indirectness and publication bias—for the potential **downgrade**[G] of the certainty of evidence for each outcome. See **Table 11** for a definition of each of these certainty criteria.

Table 11: GRADE Certainty Criteria

QUALITY CRITERIA	DEFINITION
Risk of bias	Limitations in the study design and execution that may bias study results. Valid and reliable quality appraisal tools are used to assess the risk of bias. First, risk of bias is examined for each individual study and then examined across all studies per defined outcome.
Inconsistency	Unexplained differences (heterogeneity) of results across studies. Inconsistency is assessed by exploring the magnitude of difference and possible explanations in the direction and size of effects reported across studies for a defined outcome.
Indirectness	Variability between the research and review question and the context within which the recommendations would be applied (applicability). There are four sources of indirectness which are assessed: ■ Differences in population. ■ Differences in interventions. ■ Differences in outcomes measured. ■ Differences in comparators.
Imprecision	The degree of uncertainty around the estimate of effect. This is usually related to sample size and number of events. Studies are examined for sample size, number of events and confidence intervals.
Publication bias	Selective publication of studies based on study results. If publication bias is strongly suspected, downgrading is considered.

Source: Schunemann H, Brozek J, Guyatt G, Oxman A, editors. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach [Internet]. [place unknown]: The GRADE Working Group; 2013. Available from: https://gdt.gradepro.org/app/handbook/handbook.html#h.svwngs6pm0f2

After considering the five criteria outlined in **Table 11**, three factors are assessed that can potentially enable rating up the certainty of evidence for observational studies:

1. **Large magnitude of effect:** If the body of evidence has not been rated down for any of the five criteria and a large estimate of the magnitude of intervention effect is present, there is consideration for rating up.
2. **Dose–response gradient:** If the body of evidence has not been rated down for any of the five criteria and a dose–response gradient is present, there is consideration for rating up.
3. **Effect of plausible confounding:** If the body of evidence has not been rated down for any of the five criteria and all residual confounders would result in an underestimation of **treatment effect**[G], there is consideration for rating up (11).

GRADE categorizes the overall certainty of evidence as high, moderate, low or very low. See **Table 12** for the definitions of these categories.

For this BPG, the five GRADE certainty criteria for potentially downgrading quantitative evidence and the three GRADE certainty criteria for potentially rating up quantitative evidence were independently assessed by two reviewers. Any discrepancies were resolved through consensus. The certainty of evidence assigned to each recommendation was based on the certainty of evidence of prioritized outcomes in the studies that informed the recommendation.

Table 12: Certainty of Evidence

OVERALL CERTAINTY OF EVIDENCE	DEFINITION
High	We are very confident that the true effect lies close to that of the estimate of the effect.
Moderate	We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low	Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.
Very Low	We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

Source: Reprinted from: Schunemann H, Brozek J, Guyatt G, Oxman A, editors. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach [Internet]. [place unknown]: The GRADE Working Group; 2013. Available from: https://gdt.gradepro.org/app/handbook/handbook.html#h.svwngs6pm0f2. Reprinted with permission.

Confidence in Evidence

Similar to GRADE, CERQual has four criteria to assess the confidence in qualitative findings related to a phenomenon of interest:

1. methodological limitations,
2. relevance,
3. coherence, and
4. adequacy of data.

See **Table 13** for a definition of each of these criteria.

Table 13: CERQual Confidence Criteria

CRITERIA	DEFINITION
Methodological limitations	The extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding.
Coherence	An assessment of how clear and cogent the fit is between the data from the primary studies and a review finding that synthesises that data. Cogent refers to being well supported or compelling.
Adequacy of data	An overall determination of the degree of richness and quantity of data supporting a review finding.
Relevance	The extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question.

Source: Reprinted from Lewin S, Booth A, Glenton C, Munthe-Kass H, Rashidian A, Wainright M et al. Applying GRADE-CERQUAL to qualitative evidence synthesis findings: introduction to the series. Implement Sci. 2018;13(Suppl 1):1–10. Table 2, Definitions of the components of the CERQual approach; p. 5. Reprinted with permission.

Qualitative findings related to each of the prioritized outcomes were independently assessed by the two reviewers using the four criteria. Discrepancies were resolved through consensus. Recommendations that included qualitative evidence were assigned an overall confidence in evidence based on the corresponding review finding. See **Table 14 f**or the definitions of these categories.

Table 14: Confidence in Evidence

OVERALL CONFIDENCE OF EVIDENCE	DEFINITION
High	It is highly likely that the finding is a reasonable representation of the phenomenon of interest.
Moderate	It is likely that the finding is a reasonable representation of the phenomenon of interest.
Low	It is possible that the review finding is a reasonable representation of the phenomenon of interest.
Very Low	It is not clear whether the review finding is a reasonable representation of the phenomenon of interest.

Source: Reprinted from Lewin S, Booth A, Glenton C, Munthe-Kass H, Rashidian A, Wainright M et al. Applying GRADE-CERQUAL to qualitative evidence synthesis findings: introduction to the series. Implement Sci. 2018;13(Suppl 1):1–10. Table 3, Description of level of confidence in a review finding in the CERQual approach; p. 6. Reprinted with permission.

Summarizing the Evidence

GRADE and CERQual evidence profiles are used to present decisions on the certainty and confidence of evidence, as well as general general information about the body of research evidence, including key statistical or narrative results (182). Evidence profiles summarize the body of evidence for each systematic review per outcome and are developed by the guideline development methodologists.

Evidence profiles for the body of quantitative studies present the decisions made by the two reviewers on the five key GRADE certainty criteria for downgrading and the three GRADE certainty criteria for rating up. The evidence profiles also present general information about the body of evidence, including the population, the countries where the studies were conducted, a description of the intervention, the key results and the transparent judgments about the certainty underlying the evidence for each outcome (11). For this BPG, **meta-analyses**[G] were not performed; results were synthesized using narrative format.

CERQual evidence profiles were created for the body of qualitative evidence for each systematic review per outcome. Similar to the GRADE evidence profiles used for quantitative research, the CERQual evidence profiles presented the body of evidence supporting each theme as related to each outcome per recommendation question. These evidence profiles presented the decisions made by the two reviewers on the four key **CERQual criteria**[G] and transparent judgements about the confidence underlying the evidence for each theme.

For the GRADE and CERQual evidence profiles for each systematic review per outcome, please contact us at RNAO.ca/contact.

Formulating Recommendations

Evidence-to-Decision Frameworks

Evidence-to-Decision (EtD) frameworks[G] outline proposed recommendations and summarize all necessary factors and considerations based on available evidence and expert panel judgement for formulating the recommendation statements. EtD frameworks are used to help ensure that all of the important factors required to develop recommendation statements are considered by an expert panel (11). The guideline development methodologist drafted the frameworks with both quantitative and qualitative evidence from the systematic reviews.

For this BPG, the EtD frameworks included the following areas of consideration for each drafted recommendation statement (see **Table 15**):

- background information on the magnitude of the problem;
- includes the PICO research question and general context related to the research question;
- the balance of benefits and harms of an intervention;
- certainty and/or confidence of the evidence;
- values and preferences; and
- health equity.

Decision Making: Determining the Direction and Strength of Recommendations

Expert panel members were provided with the EtD frameworks to review prior to a scheduled two-day in-person meeting to determine the direction (i.e., a recommendation for or against an intervention) and strength (i.e., strong or conditional) of the BPG's recommendations. Expert panel members were also given access to the complete evidence profiles and full-text articles.

Using the EtD frameworks as a guiding document, the expert panel members participated in an online vote from May 14 to May 28, 2018. The following questions were posed to all expert panel members for each draft recommendation:

- Is there important uncertainty about or variability in how much people value the main outcomes?
- Does the balance between desirable and undesirable effects favor the intervention or the comparison?
- What would be the impact on health equity?

Likert scales modeled after the GRADEpro software were used for voting on each factor (183). There was also the opportunity for expert panel members to provide free-text comments related to each of the judgement criteria.

The results of the online vote were calculated and presented to the expert panel at a two-day in-person meeting held on June 6 and 7, 2018. The online vote results were used to help guide discussion to determine the required direction and strength of each recommendation. The expert panel co-chairs and guideline development co-leads facilitated the meeting to allow for adequate discussion for each proposed recommendation.

The decision on direction and strength of each recommendation statement was determined by discussion and a consensus vote of 70 per cent. The voting process was moderated by the expert panel co-chairs and guideline development co-leads. In determining the strength of a recommendation statement, the expert panel was asked to consider the following:

- the balance of benefits and harms;
- certainty and confidence of the evidence;
- values and preferences; and
- potential impact on health equity.

See **Table 15** for more on these considerations.

Following the in-person meeting, the final decisions made on all recommendations were summarized and sent electronically to the full expert panel.

Table 15: Key Considerations for Determining the Strength of Recommendations

FACTOR	DEFINITION	SOURCES
Benefits and harms	Potential desirable and undesirable outcomes reported in the literature when the recommended practice or intervention is used. "The larger the difference between the desirable and undesirable effects, the higher the likelihood that a strong recommendation is warranted. The narrower the gradient, the higher the likelihood that a conditional recommendation is warranted" (184).	Includes research exclusively from the systematic review.
Certainty and confidence of evidence	The extent of confidence that the estimates of an effect are adequate to support a recommendation. The extent of confidence that a review finding is a reasonable representation of the phenomenon of interest (185). Recommendations are made with different levels of certainty or confidence; the higher the certainty or confidence, the higher the likelihood that a strong recommendation is warranted (184).	Includes research exclusively from the systematic review.
Values and preferences	The relative importance or worth of the health outcomes of following a particular clinical action from a person-centred perspective (184). "The more values and preferences vary or the greater the uncertainty in values and preferences the higher the likelihood that a conditional recommendation is warranted" (184).	Includes evidence from the systematic review (when available) and other sources (e.g., insights from the expert panel).
Health equity	Represents the potential impact of the recommended practice or intervention on health outcomes or health quality across different populations and/or barriers to implementing the recommended practice in particular settings. The greater the potential for increasing health inequity, the higher the likelihood that a conditional recommendation is warranted.	Includes evidence from the systematic review (when available) and other sources (e.g., insights from the expert panel).

Source: Adapted by the RNAO expert panel from Schunemann H, Brozek J, Guyatt G, Oxman A, editors. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach [Internet]. [place unknown]: The GRADE Working Group; 2013. Available from: https://gdt.gradepro.org/app/handbook/handbook.html#h.svwngs6pm0f2

Drafting the Best Practice Guideline

The guideline development methodologist wrote the draft of this BPG. The expert panel reviewed the draft and provided written feedback. A teleconference was held on October 12, 2018, to review the expert panel's feedback and incorporate changes, as necessary. The BPG then proceeded to external stakeholder review.

Stakeholder Review

As part of the guideline development process, RNAO is committed to obtaining feedback from (a) nurses and other health providers from a wide range of practice settings and roles, (b) knowledgeable administrators and funders of health services, and (c) stakeholder associations.

Stakeholder reviewers for RNAO BPGs are identified in two ways. First, stakeholders are recruited through a public call issued on the RNAO website (RNAO.ca/bpg/get-involved/stakeholder). Second, individuals and organizations with expertise in the BPG topic area are identified by the RNAO Best Practice Guideline Development and Research Team and the expert panel; they are then directly invited to participate in the review.

Stakeholder reviewers are individuals with subject matter expertise in the BPG topic or those who may be affected by its implementation. Reviewers may be nurses, members of the interprofessional health team, nurse executives, administrators, research experts, educators, nursing students, or persons with lived experience and their family members.

Reviewers are asked to read a full draft of the BPG and participate in its review prior to publication. Stakeholder feedback is submitted online by completing a survey questionnaire. Stakeholders are asked the following questions:

- Is the guideline title appropriate?
- Is the guideline development process clear?

In addition, stakeholders are asked the following questions about each recommendation:

- Is this recommendation clear?
- Do you agree with this recommendation?
- Is the discussion of evidence thorough, and does the evidence support the recommendation?

The survey also provides an opportunity to include comments and feedback for each section of the BPG, including the evaluation indicators. Survey submissions are compiled and feedback is summarized by the RNAO Best Practice Guideline Development and Research Team. A teleconference with the expert panel was held to review stakeholder feedback on January 30, 2019, BPG content and recommendations were modified prior to publication to reflect the feedback received.

For this BPG, the stakeholder review process was completed from December 14, 2018, to January 11, 2019. Diverse perspectives provided feedback (see **Stakeholder Acknowledgement**).

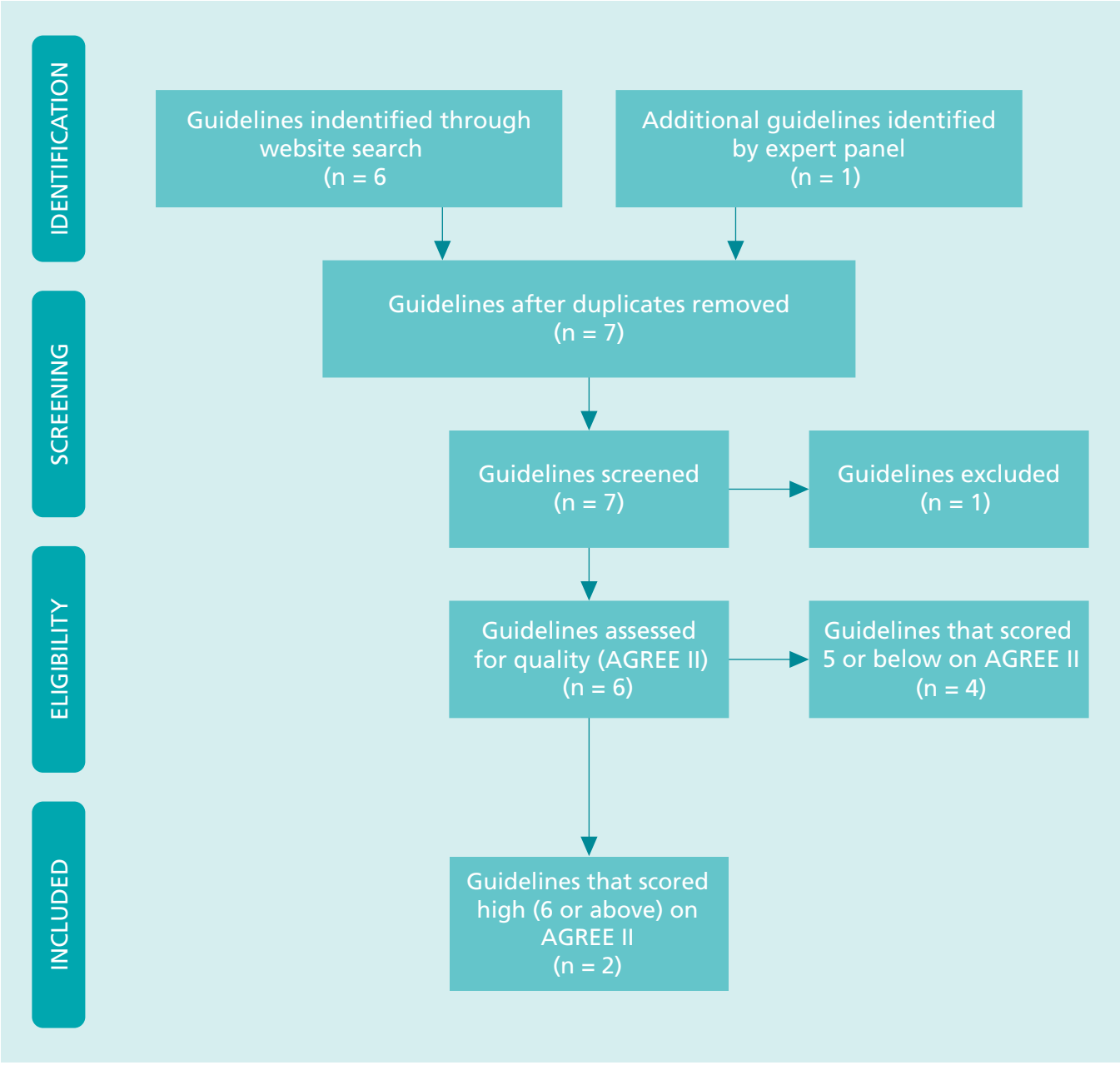
Procedure for Updating This Guideline

The RNAO commits to updating all BPGs as follows:

1. Each BPG will be reviewed by a team of specialists in the topic area every five years following publication of the previous edition.
2. RNAO International Affairs and Best Practice Guideline Centre staff regularly monitor for new systematic reviews, randomized controlled trials and other relevant literature in the field.
3. Based on that monitoring, staff may recommend an earlier revision period for a particular BPG. Appropriate consultation with members of the original expert panel, other specialists and experts in the field will help inform the decision to review and revise the BPG earlier than planned.
4. Three months prior to the review milestone, the staff commences planning of the review as follows:
   - Compiling feedback received and questions encountered during the implementation, including comments and experiences of BPSOs® and other implementation sites regarding their experiences.
   - Compiling a list of new clinical practice guidelines in the field and refining the purpose and scope.
   - Developing a detailed work plan with target dates and deliverables for developing a new edition of the BPG.
   - Identifying the potential BPG expert panel co-chairs with RNAO's CEO.
   - Compile a list of specialists and experts in the field for potential participation on the expert panel. The expert panel will be comprised of members from the original expert panel and new ones.
5. New editions of BPGs will be disseminated based on established structures and processes.

Appendix E: Process for Best Practice Guideline and Systematic Review

Figure 5: Guideline Review Process Flow Diagram



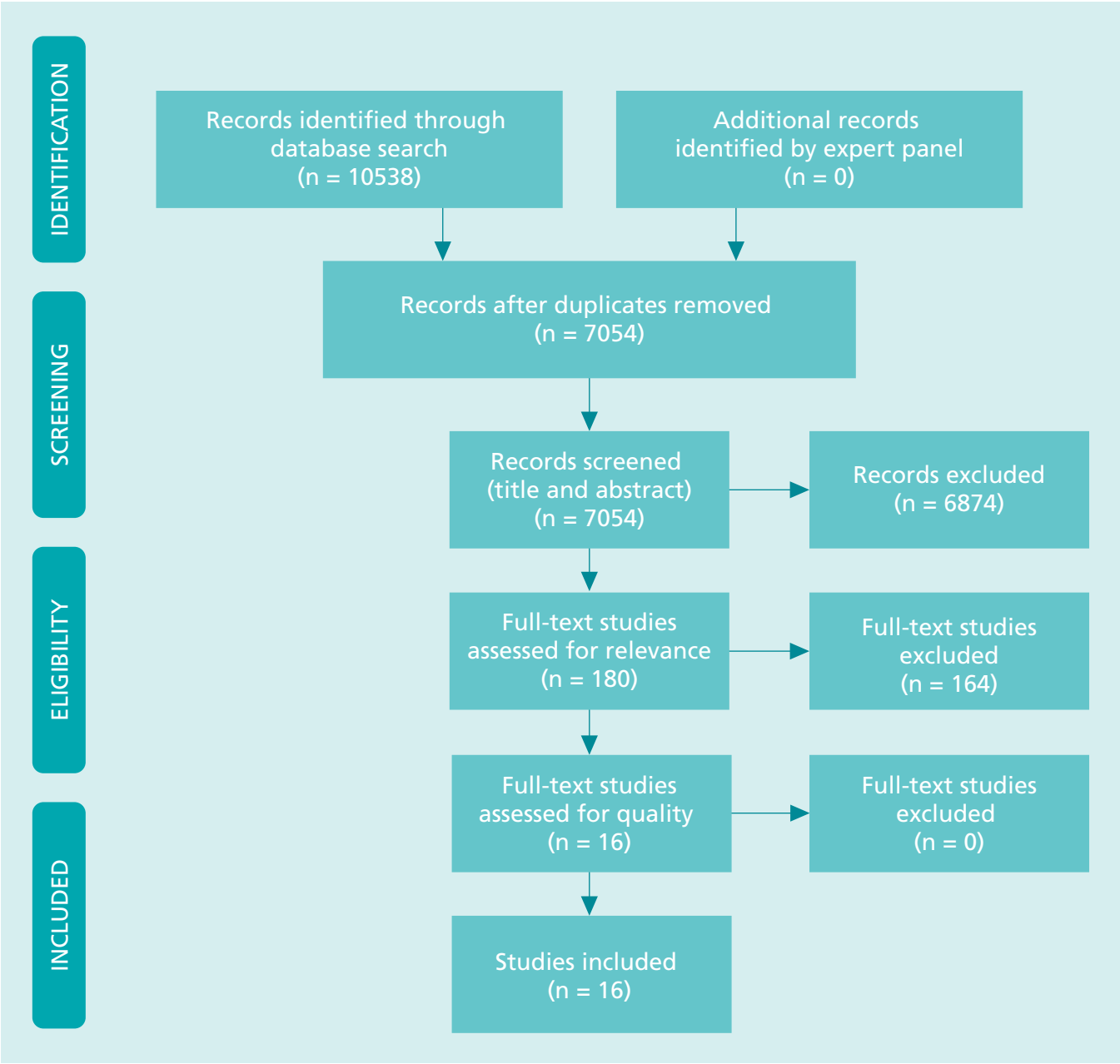
The systematic reviews that answered recommendation questions in existing high-quality guidelines (scoring 6 or 7 on AGREE II) were considered to be beyond the scope of this Guideline.

Source: Adapted by the RNAO expert panel from: Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339:b2535. doi: 10.1136/bmj.b2535.

Recommendation Question #1: Should an interprofessional approach be recommended for the provision of care to adults in the last 12 months of life?

Outcomes: Person and family experience with care provided, effectiveness of provided care from the person and family perspective, access to care, coordination of care, transitions in care, effectiveness of provided care from health provider perspective

Figure 6: Article Review Process Flow Diagram for Recommendation Question #1

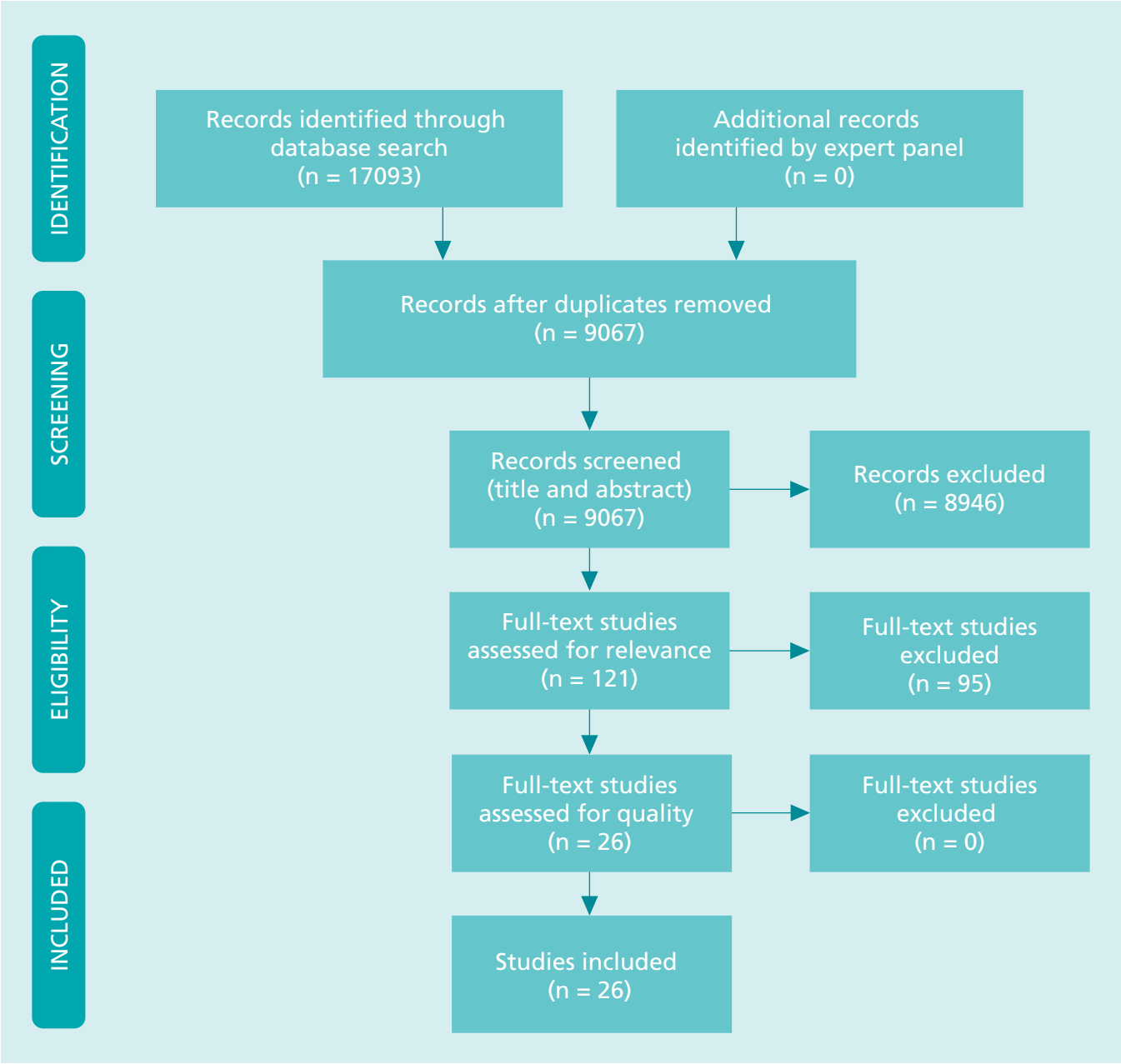


Source: Adapted by the RNAO expert panel from: Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339:b2535. doi: 10.1136/bmj.b2535.

Recommendation Question #2: What nurse-led interventions should be recommended for a palliative approach to the delivery of care in the last 12 months of life?

Outcomes: Support for spiritual care, support for emotional care, support for existential care, care in alignment with the person's wishes, culturally safe care, place of death

Figure 7: Article Review Process Flow Diagram for Recommendation Question #2

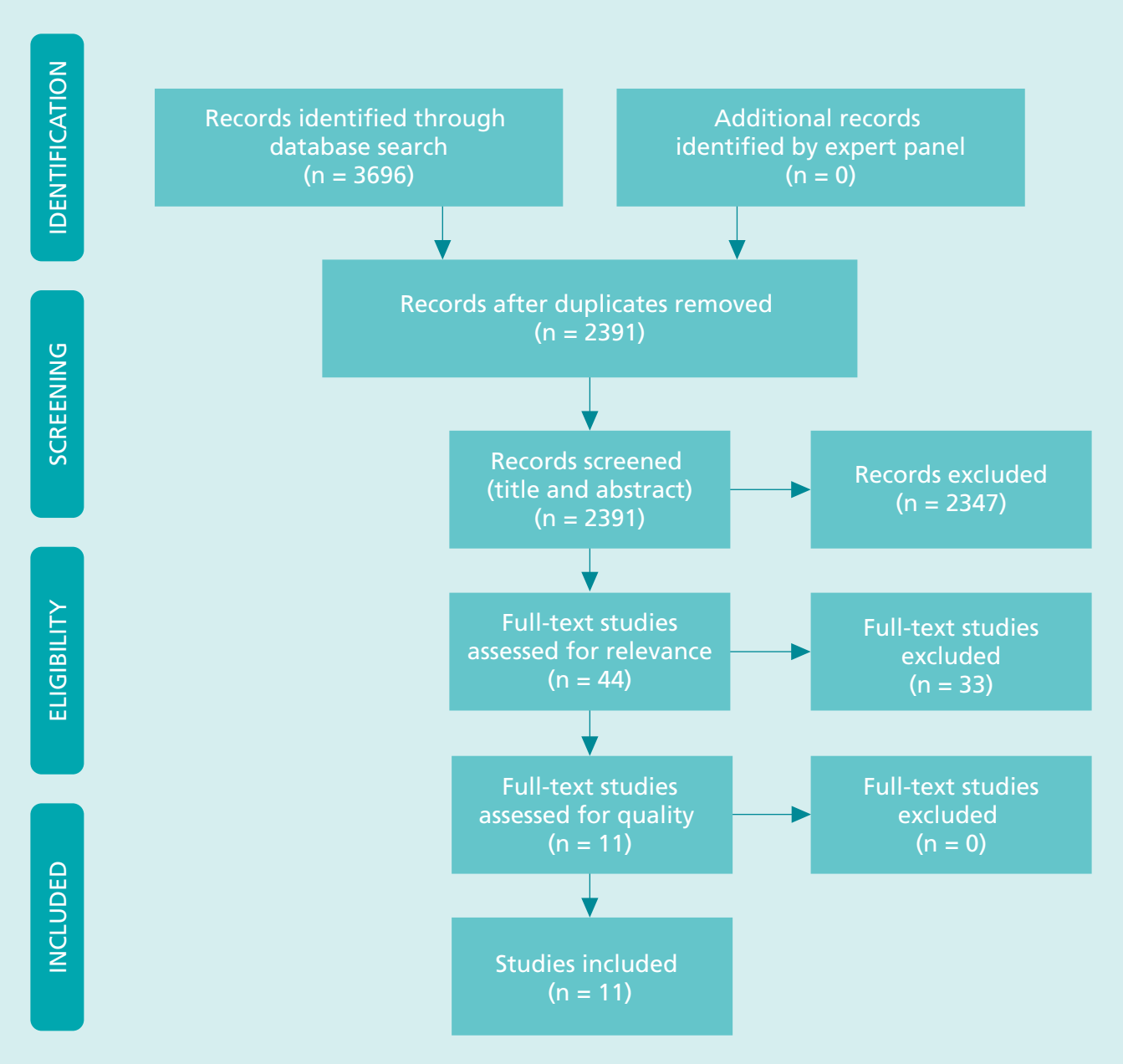


Source: Adapted by the RNAO expert panel from: Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339:b2535. doi: 10.1136/bmj.b2535.

Recommendation Question #3: Should continuing education, targeted skills training and debriefing be recommended for supporting nurses and the interprofessional health team who provide care to persons in the last 12 months of life and their families?

Outcomes: Compassion fatigue, stress/distress, resilience

Figure 8: Article Review Process Flow Diagram for Recommendation Question #3



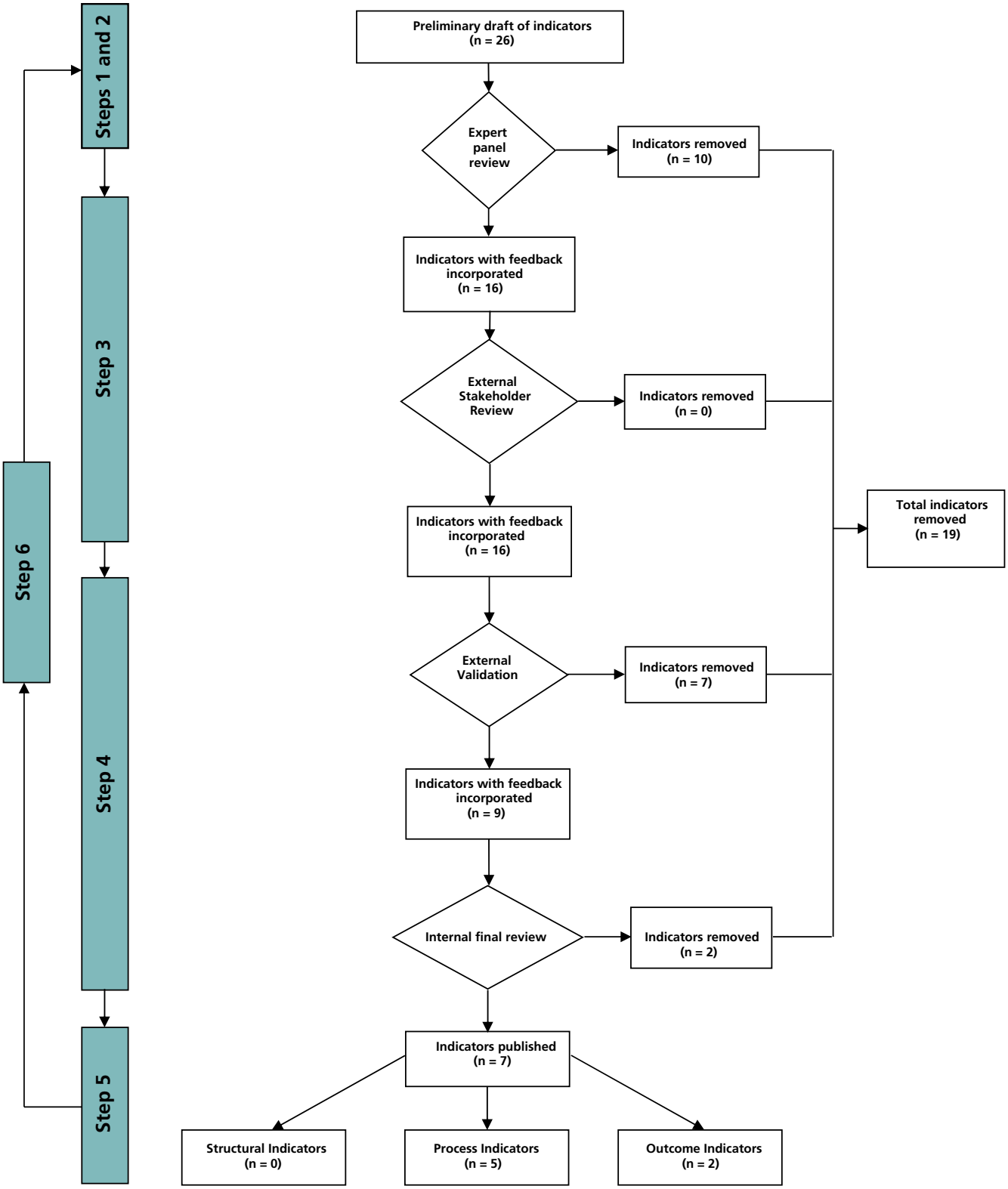
Source: Adapted by the RNAO expert panel from: Moher D, Liberati A, Tetzlaff J, Altman DG; PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. BMJ. 2009;339:b2535. doi: 10.1136/bmj.b2535.

Appendix F: Indicator Development Process

The RNAO indicator development process steps are summarized below (**Figure 9**).

1. **BPG selection:** Indicators are developed for BPGs focused on health system priorities, with an emphasis on filling gaps in measurement while reducing the reporting burden.
2. **Extraction of recommendations:** Practice recommendations, overall BPG outcomes and BPG Order Sets™ (if applicable) are reviewed to extract potential measures for indicator development.
3. **Indicator selection and development:** Indicators are selected and developed through established methodology, including alignment with external data repositories, health information data libraries and expert consultation.
4. **Practice test and validation:** Proposed indicators are internally validated through face and content validity, and externally validated by national and international organization representatives.
5. **Implementation:** Indicators are published in the Evaluation and Monitoring chart, and data dictionaries are published on the NQuIRE® website.
6. **Data quality assessment and evaluation:** Data quality assessment and evaluation, as well as ongoing feedback from BPSOs®, ensure purposeful evolution of NQuIRE indicators.

Figure 9: Indicator Development Flow Diagram



Appendix G: Tools Used to Assess Domains of Health and Illness

Table 16 provides recommendations from expert panel members and stakeholders regarding tools used to assess domains of health and illness. It is important to note that this is not a comprehensive list of all possible tools available: health-service organizations may review the table to support decision-making about the selection of approaches or tools for the setting and population(s) served.

Tools and approaches are ordered alphabetically in categories related to pain and physical symptoms, psychosocial and spiritual assessments/screening tools, and other assessment/screening tools. There is no specific ranking of tools or approaches. Inclusion of a tool in this list does not constitute an endorsement by RNAO.

Table 16: Assessment/Screening Tools

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
Note: This table provides the links to several assessment tools. Many of these tools are copyrighted. Please cite authors/sources and seek permission to re-print when using these tools.			
PAIN AND PHYSICAL SYMPTOMS			
Brief Fatigue Inventory	Tool to measure cancer-related fatigue.	http://www.npcrc.org/files/news/brief_fatigue_inventory.pdf	✓
Brief Pain Inventory	Pain assessment tool for cancer patients that explores level of pain and the degree to which it interferes with function.	Long form: http://www.npcrc.org/files/news/briefpain_long.pdf Short form: http://www.npcrc.org/files/news/briefpain_short.pdf	✓

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
Edmonton Symptom Assessment System (ESAS)	Assessment of nine symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. Also includes space for "other" symptoms.	http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf	✓
McGill Pain Questionnaire	Explores the characteristics and intensity of pain.	https://www.gem-beta.org/public/DownloadMeasure.aspx?mid=1348	✓
Memorial Symptom Assessment Scale (MSAS)	Assesses physical and psychological symptoms with regards to intensity, frequency and distress.	http://www.npcrc.org/files/news/memorial_symptom_assessment_scale.pdf Short form: http://www.npcrc.org/files/news/memorial_symptom_assessment_scale_short.pdf Condensed: http://www.npcrc.org/files/news/condensed_memorial_symptom_assessment_scale.pdf	✓
PSYCHOSOCIAL AND SPIRITUAL ASSESSMENTS/SCREENING TOOLS			
Distress Thermometer	Self-report measure that explores level of distress on a 10-point scale.	https://www.nccn.org/patients/resources/life_with_cancer/pdf/nccn_distress_thermometer.pdf	✓
FAMCARE/ FAMCARE-2	Measures family satisfaction with care of patients with advanced cancer.	http://www.palliative.org/NewPC/professionals/tools/famcare.html	✓

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
FICA Spiritual Assessment Tool	Explores spiritual history and beliefs.	https://meds.queensu.ca/source/spiritassesstool%20FICA.pdf	✓
Frommelt Attitude Toward Care of the Dying Scale	Explores how nurses feel about end-of-life care situations with persons and their families.	http://ltctoolkit.rnao.ca/sites/default/files/resources/Appendix%20G.pdf	✓
HOPE Spiritual Assessment Tool	Explores four basic areas to complete a spiritual assessment. These areas include: (1) sources of hope, strength, comfort, meaning, peace, love and connection; (2) the role of organized religion for the patient; (3) personal spirituality and practices; and (4) effects on medical care and end-of-life decisions.	https://www.aafp.org/afp/2001/0101/p81.html	
Psychosocial Assessment Tool	Psychosocial assessment tool for persons and their families.	https://www.victoriahospice.org/sites/default/files/psychosocial_assessment_tool_sample.pdf	✓
OTHER ASSESSMENT/SCREENING TOOLS			
Needs at the End-of-life Screening Tool (NEST)	Comprehensive assessment and outcome measures (explores multiple domains of illness, including spiritual).	http://www.npcrc.org/files/news/needs_end_of_life_screening_NEST.pdf	

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
Palliative Performance Scale	Measures functional level and progressive decline of a person receiving palliative care. It also appears to have some prognostic value for persons who have an advanced oncologic disease.	http://www.palliativealliance.ca/assets/files/Alliance_Reources/Physical_Care/PPS._edited_Jan_242013.pdf	✓
Patient Dignity Inventory (PDI)	Twenty-five potential concerns that should be regularly evaluated by health providers.	http://dignityincare.ca/en/toolkit.html#The_Patient_Dignity_Inventory	✓
Patient Dignity Question (PDQ)	The key question that persons working in health should consider when interacting with patients.	http://dignityincare.ca/en/toolkit.html#The_Patient_Dignity_Question	✓
PEPSI COLA AIDE MEMOIRE	Holistic patient assessment questions (from the **Gold Standards Framework**[G]).	https://www.goldstandardsframework.org.uk/cd-content/uploads/files/Library%2C%20Tools%20%26%20resources/Pepsi%20cola%20aide%20memoire.pdf	

Appendix H: Assessment Tools for Health Providers

Table 17 provides assessment tools to assess compassion fatigue and/or stress. It is important to note that this is not a comprehensive list of all possible tools available: health-service organizations may review the findings below to support decision making about the selection of a tool.

Tools are ordered alphabetically; there is no specific ranking of tools or approaches. Inclusion of a tool in this list does not constitute an endorsement by RNAO.

Table 17: Assessment Tools for Health Providers

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
Note: This table provides the links to several assessment tools. Many of these tools are copyrighted. Please cite authors/sources and seek permission to re-print when using these tools.			
Frommelt Attitude Toward Care of the Dying Scale	Explores how nurses feel about end-of-life care situations with persons and their families.	http://ltctoolkit.rnao.ca/sites/default/files/resources/Appendix%20G.pdf	✓
Life Stress Test	Explores major events occurring in the lives of caregivers in the past 12 to 24 months.	http://www.compassionfatigue.org/pages/lifestresstest.pdf	
Maslach Burnout Inventory	Measures burnout.	https://www.researchgate.net/publication/277816643_The_Maslach_Burnout_Inventory_Manual	✓
Professional Quality of Life (ProQOL)	Measures negative and positive effects of helping others who experience suffering and trauma. The ProQOL tool has sub-scales for compassion satisfaction, burnout and compassion fatigue.	https://proqol.org/ProQol_Test.html	✓

ASSESSMENT/ SCREENING TOOL	DESCRIPTION	WEBSITE	VALIDATION STUDIES LOCATED
Trauma Recovery Scale	Measures whether a person has been exposed directly or indirectly to a traumatic incident or has a history of traumatic experiences, and assesses their recovery and stabilization from traumatic experiences.	https://psychink.com/ti2012/wp-content/uploads/2012/06/207TICAssign.20111.pdf	

Appendix I: Pain and Symptom Management Resources

Table 18 includes resources related to pain and symptom management in palliative care and end-of-life care. It is important to note that this is not an exhaustive list of all possible resources available.

Table 18: Resources for pain and symptom management in palliative care and end-of-life care

ORGANIZATION	TITLE	CONTENTS	WEBSITE
BC Cancer	Symptom Management Guidelines	Nursing guidance for managing the symptoms of cancer. Interactive website that includes content related to the following: acneiform rash; anorexia and cachexia; constipation; diarrhea; dyspnea; fatigue; fever and neutropenia; intimacy and sexuality; lymphedema; malignant wounds; nausea and vomiting; oral mucositis; pain; palmar plantar erythrodysesthesia; peripheral neuropathy; radiation dermatitis; sleep–wake disturbances; and xerostomia.	http://www.bccancer.bc.ca/health-professionals/clinical-resources/nursing/symptom-management

ORGANIZATION	TITLE	CONTENTS	WEBSITE
BC Centre for Palliative Care	B.C. Inter-Professional Palliative Symptom Management Guidelines	Interactive PDF focusing on interprofessional palliative symptom management. Includes content related to the following: pain; fatigue; pruritus; severe bleeding; constipation; nausea and vomiting; dysphagia; anorexia; dehydration; respiratory congestion; dyspnea; cough; hiccoughs; twitching/myoclonus/seizures; and delirium.	https://www.bc-cpc.ca/cpc/wp-content/uploads/2018/09/SMGs-interactive-final-Nov-30-compressed.pdf
BC Guidelines	Palliative Care for the Patient with Incurable Cancer or Advanced Disease – Part 2: Pain and Symptom Management	Guideline for patients 19 years of age and older that outlines strategies to assess and manage pain due to cancer, along with symptoms associated with advanced disease. Key symptom areas addressed include: constipation; delirium; depression; dyspnea; fatigue and weakness; nausea and vomiting; and pain.	https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-pain-management

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Cancer Care Ontario	Guidelines and Advice: Managing Symptoms, Side Effects & Well-Being	Provides tools to assess and manage symptoms and side effects associated with cancer and its treatment. Also provides information for patients about maintaining well-being, how to recognize symptoms and side effects, and how to manage them.	(English) https://www.cancercareontario.ca/fr/symptom-management (French)
	Ontario Cancer Symptom Management Collaborative	Initiative to promote early identification, documentation and communication of patient symptoms. Website includes symptom assessment tools, as well as a symptom management mobile web app.	https://www.cancercareontario.ca/en/cancer-care-ontario/programs/clinical-services/patient-reported-outcomes-symptom-management/cancer-symptom-management-collaborative (English) https://www.cancercareontario.ca/fr/symptom-management (French)

ORGANIZATION	TITLE	CONTENTS	WEBSITE
National Institute for Health and Care Excellence (NICE)	Care of Dying Adults in the Last Days of Life	Includes recommendations focused on: (a) recognizing when a person may be in the last days of life; (b) communication; (c) shared decision-making; (d) maintaining hydration; (e) pharmacological interventions; and (f) anticipatory prescribing.	https://www.nice.org.uk/guidance/ng31/evidence/full-guideline-pdf-2240610301
	Managing Symptoms for an Adult in the Last Days of Life	Interactive flowchart on managing symptoms at the end of life.	https://pathways.nice.org.uk/pathways/end-of-life-care-for-people-with-life-limiting-conditions#path=view%3A/pathways/end-of-life-care-for-people-with-life-limiting-conditions/managing-symptoms-for-an-adult-in-the-last-days-of-life.xml&content=view-index
	Palliative Care for Adults: Strong Opioids for Pain Relief	Guidance for safe and effective prescribing of opioids for adults who require pain relief due to advanced and progressive disease.	https://www.nice.org.uk/guidance/cg140

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Registered Nurses' Association of Ontario (RNAO)	Assessment and Management of Pain, Third Edition	BPG on assessment and management of pain.	RNAO.ca/bpg/guidelines/assessment-and-management-pain (English) RNAO.ca/bpg/translations/%C3%A9valuation-et-prise-en-charge-de-la-douleur (French)
	Assessment and Management of Pressure Injuries for the Interprofessional Team, Third Edition	BPG for the interprofessional team on assessment and management of pressure injuries.	RNAO.ca/bpg/guidelines/pressure-injuries (English) RNAO.ca/bpg/language/l%C3%A9sions-de-pression (French)
	Delirium, Dementia, and Depression in Older Adults: Assessment and Care	BPG on assessment and care for delirium, dementia and depression in older adults.	RNAO.ca/sites/rnao-ca/files/3Ds_BPG_WEB_FINAL.pdf
	End-of-Life Care During the Last Days and Hours	BPG on end-of-life care during the last days and hours.	RNAO.ca/sites/rnao-ca/files/End-of-Life_Care_During_the_Last_Days_and_Hours_0.pdf
	Prevention of Constipation in the Older Adult Population	BPG on the prevention of constipation in the older adult population.	RNAO.ca/bpg/guidelines/prevention-constipation-older-adult-population (English) RNAO.ca/bpg/translations/pr%C3%A9vention-de-la-constipation-chez-les-personnes-%C3%A2g%C3%A9es (French)
World Health Organization (WHO)	Palliative Care: Symptom Management and End-of-life Care	A module that guides health workers on how to provide palliative care treatment and advice in a clinic, and provides supports to caregivers and family members who need to provide palliative care in the home environment.	http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf

Appendix J: Education and Competency Resources

Table 19 contains a list of resources that provide information about education and competencies related to palliative care and end-of-life care. It is important to note that this is not an exhaustive list of all possible resources available.

Table 19: Resources for palliative care and end-of-life care education and competencies.

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Canadian Nurses Association	Exam Blueprint and Speciality Competencies	Exam blueprint and specialty competencies for the Hospice Palliative Care Nursing Certification Exam.	https://www.cna-aiic.ca/-/media/nurseone/files/en/hospice_palliative_care_blueprint_and_competencies_e.pdf?la=en&hash=EF462BF689939CEA1CE13614E280CEE9448956FB
Canadian Virtual Hospice	Tools for Practice	Protocols, advanced practices, assessment and evaluation tools to support health providers. Tools are separated into various topics, including: Indigenous palliative care, advanced care planning, communication, dying at home, education, etc.	http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/Tools+for+Practice.aspx
Centre for Palliative Care	Palliative Care: Getting Started	Free online course for health professionals that introduce the key concepts in palliative care needed to provide best practice clinical care.	https://www.centreforpallcare.org/page/31/online-courses

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Future Learn	Palliative Care: Making it Work	Online course that outlines how palliative care is managed in Europe, and what are best practices when delivering integrated palliative care.	https://www.futurelearn.com/courses/palliative
Government of Canada	Framework on Palliative Care in Canada	Palliative care training and education for health providers and other caregivers.	https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p2.3.1
Health Quality Ontario: Ontario Health Technology Assessment Series	Educational Interventions in End-of-Life Care: an Evidence-based Analysis	A study on the effectiveness of educational interventions for health care providers, patients nearing the end of life, and informal caregivers to improve patient and informal caregiver outcomes.	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4552297/
St. Joseph's Healthcare London	Comprehensive Advanced Palliative Care Education (CAPCE) Program	Program designed to align with the Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice.	https://www.palliativecareswo.ca/programs-CAPCE.html

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Nova Scotia Health Authority	The Nova Scotia Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers	Palliative care competency framework created to support implementation of the Nova Scotia Integrated Palliative Care Strategy, emphasize the fact that palliative care is interprofessional, and guide the selection, tailoring and creation of education programs.	http://spiritualcare.ca/download/nova-scotia-palliative-care-competency-framework-2017/?wpdmdl=9810
Ontario Palliative Care Network	The Ontario Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers	Outlines the knowledge and skills that health providers need to deliver high-quality palliative care.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNCompetencyFramework.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNCompetencyFrameworkFR.pdf (French)
Palliative Care Competence Framework Steering Group	Palliative Care Competence Framework	Framework to support health providers across health care settings to engage in self-assessment, and develop and maintain the skills, knowledge and attributes that are necessary to provide palliative care.	http://aiihpc.org/wp-content/uploads/2015/02/Palliative-Care-Competence-Framework.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Pallium Canada	Learning Essential Approaches to Palliative Care (LEAP) Training	A two-day course for health professionals who work in the community and who may care for patients with life-threatening and progressive life-limiting illnesses.	https://pallium.ca/equip-yourself/courses/
	Taking Ownership in Palliative Care	Module for health professionals that includes the following topics: identifying when a patient could benefit from palliative care; how to identify patients early; changing the culture; and who can provide palliative care.	https://pallium.ca/Taking_Ownership_Preview/story_html5.html
ARTICLES AND BOOKS			
Pesut B, Greig M. Resources for educating, training, and mentoring nurses and unregulated nursing care providers in palliative care: a review and expert consultation. J Palliat Med. 2018;21(S1):S50-6.		This review examines resources required to ensure adequate education, training, and mentorship for nurses and nursing care providers who care for Canadians experiencing life-limiting illness and their families.	
Lowey, S. Nursing Care at the End of Life: What Every Clinician Should Know. New York: The College at Brockport, SUNY, 2019. http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/Tools+for+Practice/Ethics/Nursing+Care+at+the+End+of+Life_+What+Every+Clinician+Should+Know.aspx		A textbook for registered nursing students that looks at death and dying, and how nurses can assist patients and families during their journey towards end of life. Includes: overview of death and dying; historical examination of some of the conceptual models associated with how patients cope with impending loss; illness trajectories and models of care; and evidence-based approaches for pain and symptom management, ethical concerns, cultural considerations, care at the time of death, and grief/bereavement.	

Appendix K: *The Ontario Palliative Care Competency Framework*—Nursing Competencies

In 2019, the Ontario Palliative Care Network (OPCN) published a competency framework for health professionals and volunteers outlining the knowledge, personal attributes and skills needed to deliver high-quality palliative care in Ontario. *The Ontario Palliative Care Competency Framework: A Reference Guide for Health Professionals and Volunteers* is available at the links below.

English: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNCompetencyFramework.pdf

French: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNCompetencyFrameworkFR.pdf

Due to the length of the competency framework, this appendix includes only the competencies relevant to nurses in all practice settings and nurses specializing in palliative care.

Palliative Care Competencies for Nurses in All Practice Settings (RN, RPN, CNS & NP)

Principles of Palliative Care

- Demonstrates understanding of the philosophy of palliative care.
  - Provides culturally relevant explanations about palliative care particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
- Demonstrates understanding that a palliative approach to care starts early in the trajectory of a progressive life-limiting condition, and may be appropriate at the time of diagnosis.
- Demonstrates ability to describe the meaning of the term "life-limiting condition."
- Identifies individuals who would benefit from a palliative approach early in a life-limiting condition.
- Applies the principles of palliative care that affirm life, offers a support system to help individuals live as actively as possible until death, with optimal quality of life and helps families cope during illness and bereavement.
- Conserves and promotes dignity of the person by facilitating expression of needs, hopes, feelings and concerns when planning palliative care.
- Recognizes the role of primary and acute care in the provision of palliative care across a variety of settings.
- Demonstrates understanding of the role and function of the Interdisciplinary Care Team in palliative care.
  - Demonstrates understanding of the role and function of the Specialist Palliative Care Team, including volunteers.
- Demonstrates understanding of the guiding principles of First Nations, Inuit, Métis and urban Indigenous care teams.
  - Recognizes the contribution of community strengths, gaps and barriers in building palliative care teams within First Nations, Inuit, Métis and urban Indigenous communities and that care teams will be specific to each community.

- Demonstrates understanding of palliative care standards, guidelines and policies.
- Demonstrates understanding of the Ontario Drug Benefits Formulary, and the Palliative Care Facilitated Access mechanism.

Cultural Safety and Humility

- Demonstrates understanding of the influence of culture on key issues in palliative and end-of-life care.
  - Understands health, wellness, and serious illness from diverse perspectives particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
  - Examines attitudes towards death particularly for First Nations, Inuit, Métis and urban Indigenous peoples/communities and how it compares to Western Views/Society.
- Demonstrates understanding of the Indigenous Wellness Framework.
- Demonstrates openness and sensitivity to social, spiritual and cultural values and practices that may influence individual and family preference and accommodates these.
- Recognizes personal biases and values that may influence care and identifies mechanisms to overcome these to ensure they do not impact care and treatment.
- Assesses the unique needs and preferences of the individual and their family, considering the social determinants of health, as well as their ethnicity, culture, gender, sexual orientation, language, religion, spirituality, age and ability.
- Validates and preserves cultural preferences and values by identifying ways to incorporate them into goal setting, decision making and care planning.
- Recognizes and respects who the person identifies as family, and responds to family members' unique needs and experiences.
  - Considers the community as an essential component of the unit of care for First Nations, Inuit, Métis and urban Indigenous peoples.
- Explores the person and their family's cultural and religious needs, beliefs and preferences as they relate to end-of-life.
- Creates an environment and provides opportunities for the person and their family to exercise religious, cultural and spiritual rituals, customs, rites and beliefs throughout the person's illness and through bereavement.

Communication

- Introduces individuals and their families to the concept and benefits of palliative care, along with other disease ameliorating treatments, or as the main focus of care.
- Demonstrates understanding of the essential role communication plays in palliative care.
- Demonstrates understanding that communication regarding palliative and end-of-life care is an on-going collaborative process.
  - Understands and recognizes that for First Nations, Inuit, Métis and urban Indigenous communities, the individual and family are the most important members of the care team and acknowledges the importance of on-going communication between the health care providers and the family.
- Recognizes the multidimensional communication challenges may that arise when caring for people with life-limiting conditions.

- Assesses the person's and family's understanding of the life-limiting condition.
- Recognizes the potential for conflict in palliative care decision-making and contributes to its management.
- Supports individuals to make informed decisions on the depth of information about diagnosis, prognosis and disease progression they wish to receive and share with their families.
- Provides culturally relevant information and resources to support individuals and families, particularly when caring for those from First Nations, Inuit, Métis and urban Indigenous communities.
- Invites, facilitates and respects the involvement of the person, their family and their care team in discussions regarding the plan of care.
  - Recognizes that communication and decision-making may involve the larger community, particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples, and supports facilitation of this.
- Recognizes that family conversations may involve children and different communication approaches may be required.
- Evaluates communication with the person and their family/caregiver to ensure their care plan meets the person's identified needs.
- Identifies the importance of community care plans when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
- Applies requisite relational skills (e.g., negotiating, listening, clarifying) to support decision making and suggesting modes of palliative care on an ongoing basis.
- Maintains open communication channels with First Nations, Inuit, Métis and urban Indigenous care teams when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
- Influences the discharge planning process to facilitate smooth transitions particularly when caring for First Nations and Inuit people and dual providers may be involved.
- Recognizes and mitigates potential barriers and limitations to supporting transitions between specialty care and primary care, particularly in First Nations, Inuit, Métis and urban Indigenous communities.
- Creates opportunities for the person to conduct a life review, either through use of individual skills or referral to other professionals.
- Adapts communication and information sharing to the unique needs of the person and their family, and engages specialist support as needed to bridge communication barriers (e.g., interpreters, sign language interpreters and assistive technology).
  - Understands the role and importance of experienced translators for individuals with language barriers, particularly First Nations, Inuit, Métis and urban Indigenous peoples, and how to access their services to ensure strong communication and understanding between health care providers and the individual/family.
  - Recognizes translation is not interpretation and understanding.
- Reviews and clarifies the person's and family's (and/or caregiver's) understanding of palliative care information presented by other providers.
- Offers the individual and/or family an opportunity to connect with the Trillium Gift of Life Network to discuss eligibility for body, organ or tissue donation.

Optimizing Comfort and Quality of Life

- Demonstrates understanding of how the palliative approach can enhance the assessment and management of symptoms.
- Recognizes common trajectories of life-limiting conditions, including common symptoms.
- Anticipates and predicts the needs of the person who has been diagnosed with a life-limiting condition based on known disease trajectories.
- Applies intra- and inter-professional approaches to optimize comfort and enhance quality of life of the person and family.
- Understands the concept of "total pain" and associated impact to the person and family.
- Understands common symptoms, other than pain, including but not limited to fatigue, cachexia, anorexia, muscle weakness and lymphedema.
- Demonstrates knowledge of the pathophysiology of pain.
- Distinguishes pain classifications and their importance in effective management.
- Applies the principles of pain and symptom management.
- Demonstrates understanding of the potential barriers to providing pain management, particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
- Regularly screens for symptoms and needs.
  - Uses standardized instruments regularly and appropriately to screen and assess symptoms and needs.
  - Recognizes that symptoms and symptom meaning is highly subjective and should be assessed and understood from a person-centered perspective particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
  - Uses investigations appropriately, according to the trajectory of life-limiting conditions.
  - Evaluates the outcomes of pain and symptom management against baseline assessment.
- Conducts assessments of the person's and their families' emotional, psychological, social, spiritual and practical strengths and needs.
  - Identifies priorities and concerns in collaboration with the person and family, taking into account their coping strategies and perception of diagnosis.
  - Attends to psychosocial and practical issues.
  - Consults with and/or refers to other providers when identified needs are beyond individual competencies or legislative scope of practice.
- Assesses and shares the benefits, burdens and risks of clinical interventions.
  - Proposes options, based on the persons preferences and expressed wishes, and discusses these with the person, or if not capable to make decisions, with their Substitute Decision Maker.
- Implements treatment plans that are consistent with the individuals expressed wishes, identified goals of care and the trajectory of their life-limiting condition.
- Uses non-pharmacological symptom management to promote comfort and quality of life.
  - Recognizes the importance of Traditional Medicine, particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples.

- Discusses, teaches and assists the person and their family with the management of pain and symptoms, including the recognition of areas needing further assessment.
- Recognizes the ways in which individuals can be engaged in self-management of their condition.
- Recognizes the need for a change in the focus of care and treatment goals at critical decision points in the course of a life-limiting condition.
- Interprets the impact of family role change when formulating relevant and realistic care plans.
- Recognizes and anticipates the physical, psychological, social and spiritual issues that affect the person and their family.
- Evaluates interventions within the care plan, discusses with the interprofessional team and proposes alternatives if necessary and as appropriate.
- Demonstrates understanding of the pathophysiology of palliative care emergencies.
- Identifies, assesses and manages palliative care emergencies including, but not limited to: biliary, bowel and urinary obstruction, catastrophic bleed, delirium, hypercalcemia, pain crisis, seizures, Spinal Cord Compression and Superior Vena Cava Obstruction.
- Supports the person, family, Substitute Decision Maker (SDM) and care teams with end-of-life decision making, including withdrawing or withholding interventions.
- Demonstrates awareness of one's own responses in the presence of a person who is nearing the end of life.
- Provides care in a compassionate manner.

Care Planning and Collaborative Practice

- Identifies how interprofessional practice enhances individual outcomes.
- Understands the collaborative relationship between the person, health professionals, family and caregivers.
  - Recognizes that care planning and decision-making may need to involve the family and larger community, particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples, and supports facilitation of this.
- Collaborates with the care team to manage pain and symptoms effectively based on the persons identified goals of care.
- Understands the Health Care Consent Act, 1996, and understands that a health provider must obtain informed consent from the person (or, if they are incapable, their Substitute Decision Maker) for any treatment or intervention proposed.
- Understands how a Substitute Decision Maker (SDM) is determined (based on the hierarchy within the Health Care Consent Act, 1996) and the role the SDM plays in making health care decisions if the person is not capable.
- Engages in conversations with individuals and their families about the role of the Substitute Decision Maker to help them understand the legislation.
- Supports the person to express their wishes and/or identify goals of care.
- Facilitates the active involvement of the person in goal setting, decision making and informed consent to support the best possible outcomes and quality of life.
- Understands the importance of determining capacity prior to conversations with individuals regarding Advance Care Planning, Goals of Care and Health Care Consent.

- Anticipates factors/conditions that may affect the individuals cognition and functional capacity to make decisions including health status changes, and towards end-of-life.
- Demonstrates ability to incorporate the person's expressed wishes, values and goals into their plan of treatment, and reviews and revises the plan, as needed, to reflect the person's current condition.
- Facilitates informed decision-making and consent by the person (or, if incapable, their Substitute Decision Maker) regarding place of care, while identifying risks in a supportive manner.
- Demonstrates responsiveness to the person's needs and preferences, acknowledging that their priorities can shift as their condition and health status changes.
- When able, provides care in the person's preferred place, while recognizing the complexities and challenges involved for the person, the family and their caregiver(s).
- Provides verbal and written information regarding the dying process, settings of death and after death care.
- Recognizes clinical and personal limitations and professional boundaries and refers to other colleagues appropriately and in a timely manner.

Last Days and Hours

- Aware of best practices for expected death, such as the Registered Nurses' Association of Ontario's Best Practice Guidelines [*Palliative Approach to Care in the Last 12 Months of Life and End-of-life Care During the Last Days and Hours*], as well as local and organizational policies and processes.
- Assists the person and their family to prepare for the time of death.
  - Supports planning for expected deaths, particularly when caring for First Nations, Inuit, Métis and urban Indigenous peoples in the community.
- Anticipates, recognizes and responds to the signs of imminent death.
- Provides information and assurance to the person and family regarding expected changes, and comfort measures during the last days and hours of life.
- Understands pronouncement of death (in accordance with regulations) in expected and unexpected deaths.
- Facilitates discussion with appropriate professional if an autopsy is required or requested.
- Assesses and respects the family's need for privacy at the time of death, offering presence as appropriate.
  - Supports the family's wishes and death rituals.
- Provides opportunities for family and the extended community to gather and be together, particularly when caring First Nations, Inuit, Métis and urban Indigenous peoples.
- Identifies situations when the Coroner must be contacted, and discusses with families in advance, if appropriate.

Loss, Grief and Bereavement

- Identifies types of grief and recognizes associated signs and symptoms.
- Demonstrates knowledge of diverse perspectives on grief, loss, bereavement and mourning to support others from a cross-cultural perspective.
  - Recognizes the impact of colonization, historical loss and trauma when caring for First Nations, Inuit, Métis and urban Indigenous peoples.
- Recognizes the range of individual physical, psychological, spiritual, emotional and social responses to loss and grief in self and others.

- Understands dimensions of grief and recognizes the factors that may increase the risk of complicated grief.
  - Understands cumulative grief, which can be particularly significant in First Nations and Inuit communities.
- Uses therapeutic conversations when supporting individuals and families experiencing loss and grief.
- Accurately assesses and manages individual's and families' loss, grief and bereavement needs, through interventions or referring to members of the interdisciplinary team.
- Provides appropriate guidance, support and information to families, caregivers, and others, based on awareness of culture and needs, and makes referrals to bereavement services, as required.

Professional and Ethical Practice

- Anticipates and addresses ethical and legal issues that may be encountered when caring for individuals with life-limiting conditions.
- Establishes and respects people's wishes regarding their care options and preferences.
- Respects the person's decisions regarding initiating, not initiating, withholding and withdrawing dialysis, hydration, nutrition support, resuscitation and other life-prolonging/life-sustaining interventions.
- Recognizes when personal beliefs, attitudes and values limit one's ability to be present and provide person-centred care; collaborates with others to ensure optimal care is provided.
- Demonstrates knowledge of and proficiency with relevant legislation and policies, e.g., Medical Assistance in Dying (MAiD), Child, Youth and Family Services Act, Adult Protection Act, the Health Care Consent Act, 1996, and the Substitute Decision Act.
- Understands distinctions among ethical and legal concepts, such as: the principle of double effect, Palliative Sedation Therapy and MAiD.
- Responds to inquiries regarding MAiD in accordance with regulatory body's relevant guidelines and standards and employer policies.[1]
- Accesses resources to ethically guide complex situations and implements possible resolutions.

Self-care

- Explores own attitudes regarding death, dying and caring for individuals with palliative care needs.
- Demonstrates awareness of the impact of past experiences of suffering, death and dying when providing palliative care.
- Demonstrates awareness of ways to manage and cope with the impact of dying and death.
- Demonstrates awareness of the emotional and spiritual supports available.
- Understands and attends to own emotional responses that result from caring for individuals with palliative care needs, including signs of loss, grief and bereavement.
- Recognizes compassion fatigue in self and colleagues; intervenes and refers appropriately.
- Engages in healthy activities that help prevent compassion fatigue.
- Demonstrates understanding of the concept of good "helping relationships" when working with First Nations, Inuit, Métis and urban Indigenous peoples.
- Demonstrates understanding of the concept of companioning, particularly when working with First Nations, Inuit, Métis and urban Indigenous peoples.

[1] [Registered nurses] and [registered nurse practitioners] can participate by providing nursing care and aiding [a nurse practitioner] or physician to provide a person with MAiD in accordance with the law.

- Participates in community-driven debriefs, particularly when working with First Nations, Inuit, Métis and urban Indigenous peoples.

Education and Evaluation

- Contributes to the evaluation of the quality of palliative care and the effectiveness of the palliative care system.
- Critically evaluates outcomes against standards and guidelines.
- Participates in palliative care continuing education opportunities.
- Participates in First Nations, Inuit, Métis and urban Indigenous cultural competency training opportunities.

Additional Competencies for Nurses Specializing in Palliative Care

Nurses specializing in palliative care may be members of a Specialist Palliative Care Consult Team, practice in a Palliative Care Unit or Hospice or practice in settings where the vast majority of individuals require palliative care. These competencies are meant to build on the foundational palliative care competencies for nurses in all practice settings [outlined above].

Principles of Palliative Care

- Facilitates empathic and responsive relationships between those experiencing life-limiting conditions and their care teams.
- Demonstrates leadership that encourages colleagues to foster a caring environment that supports all staff working in sensitive situations.
- Applies a dignity conserving approach to care when providing support.
- Practices person-centred palliative care that incorporates the unique contributions of the family and caregivers.
- Identifies and addresses beliefs and attitudes of society and health professionals towards palliative care that undermine access to high quality palliative care.
- Addresses misperceptions that the person, their family, their caregiver(s) and colleagues have about palliative care.

Communication

- Uses a variety of strategies to engage in compassionate, individualized and timely communication with the person, their family, their caregiver(s) and members of their care team.
- Assesses the person's/family's understanding of the life-limiting condition, and its trajectory and uses this to inform their communication approach.
- Maintains ongoing communication with the person, family and their care teams regarding end-of-life plan of care.
- Identifies the person's and family's information needs and preferences prior to providing information and discussing diagnosis and prognosis.
  - Assesses health literacy.
  - During essential conversations, regularly inquires whether information is meeting the person's and family's needs.
  - Responds to family requests not to share information with the person regarding diagnosis, prognosis and other information.
  - Explores the person's/family's understanding of the expectations and wishes, prognosis and goals of care.

- Assesses and discusses prognosis and trajectory of a life-limiting condition on an ongoing basis.
- Supports patients and families through uncertainty, using knowledge of the impact of disease and associated treatments to discuss care options and coping strategies.
- Facilitates ongoing discussions regarding goals of care.
  - Reviews goals of care, particularly when changes occur in disease status and functional level.
  - Addresses conflicts between personal and family expectations regarding prognosis and treatment options.
  - Nurtures hope, relative to individual meaning and quality of life, in a way that is congruent with the trajectory of the life-limiting condition.
  - Promotes realistic goal setting in a way that is congruent with the trajectory of the life-limiting condition.
  - Discusses resuscitation preferences.
  - Discusses preferred settings of care and death.
- Shares difficult news in a compassionate and supportive manner.
- Identifies situations that may benefit from a family meeting, and facilitates, when appropriate.
- Responds to concerns regarding starvation and dehydration at end-of-life.
- Responds appropriately to the person's and family's questions regarding expected death.
- Has knowledge of family dynamics and theories, including models for supporting families in crisis.
- Has in-depth knowledge of dying, death, grief, loss and bereavement and can recognize and respond to grief reactions.
- Explores questions and concerns expressed by the person and their family regarding the dying process and provides information about what to expect.
- Documents discussions and informs other care providers of key points of discussions.

[Nurse Practitioner-specific] Competencies

- Facilitates conversations to support end-of-life decision making and informed consent.
  - Presents the person with care and treatment options and their anticipated benefits, burdens and risks, considering the person's identified Goals of Care.
  - Discusses withholding and withdrawing treatments to ensure that treatment decisions are informed and align with identified goals of care.
  - Establishes resuscitation preferences (if resuscitation as part of the treatment plan or not) and obtains consent when appropriate.
- Informs the person and family of anticipated progression of disease and other complications.

Optimizing Comfort and Quality of Life

- Applies comprehensive knowledge and understanding of the clinical presentation and disease trajectories of life-limiting conditions when responding to complex and multidimensional care needs, in order to comprehensively identify current and prospective clinical issues in palliative care.
- Uses evidence-based tools to facilitate earlier identification of individuals who may benefit from palliative care.
- Draws from advanced education, knowledge and skill in palliative care to deliver holistic person-centred care.
  - Integrates physical, social, psychological and spiritual domains.
  - Explores the impact of a life-limiting condition on the different facets of a person's life and the lives of family and caregivers.

- Incorporates "quality of life," as defined by the person, as a key outcome of care.
- Uses research and audit to determine evidence of best practice as a rational for care interventions.

- Acknowledges the cumulative losses inherent in the experience of a life-limiting condition and its impact on the person and family.
- Uses evidence informed tools to regularly screen for symptoms and needs.
  - Performs comprehensive, systems-based, physical assessments and postulates causes of symptoms and conditions.
  - Conducts histories and physical exams specifically focusing on the impacts of a life-limiting condition.
  - Uses investigations appropriately, according to the trajectory of the life-limiting condition and in a manner that is consistent with goals of care and within the scope of practice.
  - Formulates assessment priorities to inform management plan.
  - Supports and guides junior or generalist staff with implementation of the care plan.
- Demonstrates comprehensive knowledge of the special considerations of pain and symptom assessment and management for children, older adults and persons with special needs.
  - Demonstrates in-depth understanding of non-pharmacological interventions.
  - Recognizes use and potential impact of Complementary and Alternative Medicines (CAM) for pain and symptom management.
  - Supports the person's decision to use CAM.
  - Reinforces the importance of accurate information and open communication to aid in decision-making.
  - Addresses requests for information on CAM.
  - Encourages the person to share CAM use with the team to assess compatibility and safety.

Screens, Assess and Manages Pain

- Knows underlying mechanisms of pain, pathophysiology and impact of total pain.
- Applies appropriate medication administration techniques relative to the types and severity of the person's pain and condition, recognizing oral route is best practice if applicable.
- Identifies and addresses barriers to pain assessment and management, including the misconceptions of the person, family and health professional.
- Identifies and addresses health system barriers to pain assessment and management.
- Demonstrates a comprehensive in-depth understanding of the pharmacological and physiological use of adjuvant medications in managing pain and symptoms.
- Demonstrates a comprehensive knowledge of common pain and symptom management medications and consults with other providers to guide management of potential side effects, interactions or complications.
- Evaluates and revises the individual's pain management goals and plan of care in collaboration with the individual and the interdisciplinary care team.
- Understands mechanisms of action of opiate drugs.
  - Addresses fears and concerns that the person may have about opioid medications.
  - Uses equianalgesic dose conversion tables for verifying opioid rotation or switching.
  - Describes the indications for opioid rotation.

- Assesses for risk of substance use disorder and manages treatment plan accordingly.
- Identifies and differentiates opioid-induced neurotoxicity (OIN) from other conditions e.g., delirium.

- Identifies individuals with difficult-to-control pain that requires further support, and refers to the Specialist Palliative Care Team or Pain Service as needed.

[Nurse Practitioner-specific] Competencies

- Uses accepted pain management guiding principles to select an appropriate analgesic regimen.
- Prescribes an appropriate first-line opioid and dose when initiating opioid treatment.
- Identifies individuals who may benefit from the addition of first-line adjuvant analgesics.
  - Prescribes an appropriate first-line adjuvant analgesic and dose in the management of neuropathic pain, visceral pain and malignant bone pain.
  - Prescribes second and third line analgesics, as required.
  - Identifies individuals who may benefit from palliative radiation therapy, and makes appropriate referrals.
  - Prevents and treats common opioid-induced side effects.
  - Titrates opioid doses appropriately.
  - Prescribes appropriate medications for breakthrough pain.
  - Switches between short-acting and long-acting formulations.
  - Implements appropriate strategies to manage Opioid Induced Neurotoxicity (OIN) as required.
- Initiates and maintains a person on methadone for pain management in collaboration with a palliative care physician, or other specialist for methadone management, if required.

Screens, Assesses and Manages Delirium

- Differentiates between delirium, dementia, depression and pain.
- Identifies, where possible and appropriate, underlying etiology, contributing factors and reversible measures.
- Implements interventions within individual competencies and legislative scope of practice, as appropriate, including hydration, antibiotics, medication changes and/or prescribes antipsychotics at appropriate doses, based on the severity of delirium, to control symptoms.
- Uses non-pharmacological approaches where possible.
- Consults with and/or refers to appropriate interdisciplinary team member(s) when beyond individual competencies, or legislative scope of practice.

[Nurse Practitioner-specific] Competencies

- Diagnoses and differentiates between subtypes of delirium.

Screens, Assesses and Respiratory Symptoms

- Identifies underlying causes and contributing factors to dyspnea.
- Manages dyspnea by addressing, when possible, underlying causes.
- Uses non-pharmacological interventions to reduce dyspnea.
- Manages upper and lower airway secretions and coughing.
- Consults with and/or refers to appropriate interdisciplinary team member(s) when beyond individual competencies or legislative scope of practice.

[Nurse Practitioner-specific] Competencies

- Diagnoses dyspnea on the basis of a person's self-reporting, rather than clinical signs, lung function tests or oxygen saturation.
- Prescribes non-pharmacological interventions to reduce dyspnea.
- Prescribes opioids, oxygen and other appropriate pharmacological approaches to control dyspnea.
- Prescribes second and third line approaches, as required.
- Prescribes non-pharmacological and pharmacological interventions to help manage upper and lower airway secretions and coughing.
- Identifies individuals who may benefit from a thoracentesis, and refers if appropriate.

Assesses and Manages Gastrointestinal Symptoms

- Knows gastrointestinal biophysiology and associated nausea and vomiting pathways.
- Identifies and addresses underlying causes and contributing factors of nausea and vomiting.
- Assess and manages constipation.
  - Identifies individuals with partial or complete malignant bowel obstruction.
  - Initiates basic management of malignant bowel obstruction when surgery is not an option.
  - Initiates constipation prevention with first-line laxative treatments.
- Assesses and manages anorexia and cachexia.
- Explores individuals' and families' concerns regarding appetite and weight loss.
  - Explains cachexia syndrome and its treatment implications.
  - Identifies reversible versus non-reversible causes of appetite loss.
  - Identifies individuals who could benefit from pharmacological appetite stimulation.
  - Identifies individuals who could benefit from artificial nutrition and those who are unlikely to benefit.
- Consults with and/or refers to appropriate interdisciplinary team member(s) when beyond individual competencies or legislative scope of practice.

[Nurse practitioner-specific] competencies

- Prescribes a first-line antiemetic drug, based on the inferred underlying mechanism and the associated neurotransmitters.
- Diagnoses constipation.
- Prescribes a laxative regimen to prevent and treat constipation.
- Identifies individuals who may benefit from a paracentesis.
- Prescribes pharmacological appetite stimulation for individuals who may benefit from this type of treatment in balance with the potential adverse effects of these therapies.

Assesses and Manages Fatigue

- Identifies reversible versus non-reversible causes of fatigue.
- Recommends evidence-based interventions for individuals with advanced disease experiencing fatigue.
- Consults with and/or refers to appropriate interdisciplinary team member(s) when beyond individual competencies or legislative scope of practice.

[Nurse practitioner-specific] competency

- Prescribes pharmacological agents to stimulate energy when appropriate.

Manages Hydration and Nutrition Concerns

- Describes the benefits and limitations of artificial hydration and nutrition.
- Identifies individuals who could benefit from artificial hydration and those who would not.
- Initiates hypodermoclysis when appropriate.
- Consults with and/or refers to appropriate interdisciplinary team member(s) when beyond individual competencies or legislative scope of practice.

[Nurse practitioner-specific] competency

- Prescribes hypodermoclysis when appropriate.

Assesses and Manages Bleeding and Thrombo-embolic Events

- Identifies individuals at risk for a hemorrhage.
- Ensures care plan includes interventions to manage a major hemorrhage, if the person is at risk based on diagnosis.
- Refers to appropriate interdisciplinary team member when beyond scope of practice.

[Nurse practitioner-specific] competencies

- Identifies individuals who could benefit from anticoagulants and prescribes if appropriate.
- Develops an approach to manage anemia and thrombocytopenia in those with advanced disease, based on goals of care and trajectory of a life-limiting condition.

Palliative Sedation Therapy

- Assesses for and recognizes intractable symptoms that may benefit from using sedation to support the person's quality of life and identified goals of care.
- Uses evidence informed interprofessional approaches to discuss sedation in palliative care, benefits and burdens, goals of care and education and teaching needs of person and family.
- Describes the ethical issues regarding Palliative Sedation Therapy.
- Collaborates with the Specialist Palliative Care Consult Team or Pain Service as needed to provide Palliative Sedation Therapy.
- Evaluates expected affects and side effects of treatment.

[Nurse practitioner-specific] competency

- Prescribes appropriate pharmacological medications and doses to initiate Palliative Sedation Therapy and assesses the individual's response.

Assesses and Manages Conditions that Constitute Emergencies in Individuals with Palliative Care Needs

- Demonstrates in-depth biophysical and disease knowledge to anticipate which conditions are more at risk of palliative emergencies.
- Anticipates, recognizes and responds to signs and symptoms of common emergencies in palliative care, and transfers to appropriate health care providers or emergency room as required.

Identifies and Addresses Psychosocial, Spiritual and Existential Needs

- Uses strategies that promote personal and spiritual growth through living with a life limiting condition.
- Assesses and manages depression and anxiety.
  - Uses validated distress screening tools to identify depression and anxiety.
  - Differentiates between normal and abnormal levels of anxiety and depression in individuals with advanced disease.
  - Identifies individuals who could benefit from pharmacological management of depression and anxiety.
  - Initiates appropriate treatment for individuals with depression and anxiety disorders given clinical context.
- Nurtures hope and meaning in a supportive way that is congruent with the individual's identified goals of care.
  - Assesses, identifies and addresses spiritual and existential needs of the person.
  - Engages appropriate spiritual and religious care providers.
- Assesses, identifies and addresses the social needs of the person and their family.
  - Assesses, validates and acknowledges the person's and family's loss and grief throughout a life-limiting condition and into bereavement.
  - Provides supportive counseling to the person and their family.
  - Identifies individuals at risk for complicated grief reactions.
  - Refers the person and their family to appropriate resources as needed.

Safe and Appropriate Medication Practices

- Demonstrates knowledge of pharmacology, pharmacokinetics and side-effects of classes of medications commonly used in palliative care.
- Assesses the efficacy of pharmacological treatments in alignment with the College of Nurses Medication Standard.
- Demonstrates understanding of the principles of dose adjustment with regard to: the frail, elderly, children, those with altered metabolism or organ failure and individuals approaching imminent death.
- Ensures the family, caregivers and care teams understand how to safely store medications and discard waste while the person is receiving care and how to safely remove medications from the home after the person has died.

[Nurse practitioner-specific] competency

- Demonstrates the ability to prescribe medications appropriate to treat a range of symptoms commonly seen in palliative care.

Care Planning and Collaborative Practice

- Collaborates with interdisciplinary care teams, primary care providers, community agencies and volunteers to meet the physical, psychological, social and spiritual needs for each person.
- Develops therapeutic relationships with the person, family, caregivers, and their care teams to define goals of care and to develop, implement and evaluate a plan of care.
  - Facilitates participation of the person in their care planning.
  - Identifies and integrates strengths of the person in their plan of care.
  - Safely and appropriately delegates aspects of care to the family.
  - Assists the family in care giving and acquiring respite care.
  - Engages in family and team conferences.
  - Develops a plan of care for the family.
  - Periodically reviews treatments, including medications, to ensure congruence with goals of care and illness trajectory.
- Assists with coordinating care and making referrals to other care team members and/or organizations e.g., visiting volunteers.
- Collaborates within and between teams across the continuum of care to facilitate continuity in palliative care.
- Identifies and supports navigation of the full range and continuum of palliative care services, resources and the settings in which they are available.
  - Collaborates with the person and family to identify resources that will provide support throughout their illness and during end-of-life care.
- Demonstrates expertise and sensitivity in facilitating safe, smooth and seamless transitions of care for the person.
  - Recognizes transition points.
  - Coordinates smooth transition between institutions, settings and services.
  - Communicates with colleagues in other settings during transitions.

- Provides palliative care in all settings where individuals reside including the home, long-term care facilities and acute care settings, such as community hospitals and [emergency departments] in rural and remote settings, group/supportive housing, shelters, jail/prison etc.
- Effectively communicates the strengths and needs of the person and family with their care teams.

Last Days and Hours

- Demonstrates a comprehensive knowledge of pain and symptom assessment and management unique to last days and hours of life.
- Assesses and manages families' and caregivers' needs through end-of-life.
- Anticipates and plans for end-of-life needs.
- Identifies individuals who are in the end of life phase.
- Assists the family to cope with emotional responses, maintain a desired level of control, share preferences and needs, determine place of death, contact significant others, access resources and communicate meaningfully in the person's last days.
- Demonstrates in-depth knowledge of caregiver exhaustion and strategies to support family resiliency including referrals to appropriate providers including respite.
- Encourages the person and their family to make timely preparations following death.
- Discusses with the family and other caregivers who to call in case of an emergency, and clarifies when 911 calls may be appropriate.
- Discusses with the family and other caregivers who to call when death occurs.
- Educates the family about the changes to expect in a person's condition at end-of-life including signs of imminent death and associated comfort measures.
- Anticipates the person's needs at end-of-life, ensuring medications and supplies are available.

Nursing specific competency

- Pronounces and arranges for certification of death.

[Nurse practitioner-specific] competency

- Timely completion of death certificates.

Loss, Grief and Bereavement

- Demonstrates a comprehensive knowledge of the grieving process and reactions in order to support patients and families throughout the disease trajectory.
- Demonstrates understanding of the needs of children of various developmental stages in dealing with grief and loss of a parent or sibling.
- Demonstrates the ability to proactively respond to complex grief reactions and processes using own skills or appropriate referral.

- Assists the family in understanding the concepts of loss, process of grief and bereavement, considering developmental stages, referring as needed.
  - Identifies types of grief.
  - Recognizes the manifestations of grief.
  - Identifies those experiencing or at risk for complicated or disenfranchised grief, and discusses, documents and refers.
  - Recognizes the differences between depression and grief.
  - Assists the family to anticipate and cope with their unique grief reactions to loss and death.
  - Assists the family to recognize the person's legacy.
  - Facilitates the family's transition into ongoing bereavement services, where indicated.
- Mentors and educates colleagues regarding the personal impact of loss, grief and bereavement, supporting them to recognize their own loss responses and encouraging engagement in activities to maintain their resilience on an on-going basis.

Professional and Ethical Practice

- Applies a comprehensive understanding of contemporary legal, ethical and professional standards to the provision of quality palliative care.
- Facilitates discussion and management of ethical and legal issues in conjunction with the person, their family, and their care team.
- Debriefs about ethical and legal issues individually and as a team, with appropriate professional(s).
- Actively influences and promotes palliative care strategic initiatives and policy development.

Education

- Educates the person, their family, and their caregiver(s) about palliative care and the palliative approach.
- Provides information appropriate to the uniqueness of the person and family regarding:
  - Disease process and illness progression.
  - Pain/symptom assessment and management.
  - Team roles.
  - Opportunities and challenges of care in specific settings.
  - Physical, psychosocial and spiritual support.
  - Treatments.
  - Dying process and death.
  - Medication administration routes.
  - Family dynamics and effective communication.
  - Age-appropriate resources regarding death, dying, loss, grief and bereavement.

- Develops, facilitates and provides palliative care related education, leadership and mentorship to members of the discipline and students.

Research and Evaluation

- Understands principles of dissemination of research and best practices to build capacity in other team members.
- Advocates for research related to the field of palliative care.
- Applies and disseminates knowledge gained from palliative care research.
- Where possible, provides the family with opportunities to participate in palliative and end-of-life care giving research.
- Where possible, leads, facilitates and engages in research in palliative care.
- Acts as an expert resource contributing to palliative care development and delivery.
- Where possible, identifies the opportunities for and barriers to discipline-specific research unique to palliative care.

Advocacy

- Advocates for the needs, decisions and rights of the person by recognizing potential vulnerabilities.
- Supports principles of autonomy and self-management.
- Promotes equitable and timely access to palliative care resources.
- Demonstrates expertise as a mediator and advocate for the person to access appropriate and timely palliative care.
- Advocates for the development, maintenance and improvement of health care and social policies related to palliative care.
- Identifies the determinants of health for the populations served and contributes to efforts to ensure equity, including, but not limited to: barriers to access to palliative care and resources, availability of primary care, interdisciplinary care teams and specialized services, delayed or lack of identification of individuals who would benefit from palliative care, lack of availability of community-based resources, geographic inequities and inequities for vulnerable and marginalized populations, poverty, cost of dying at home.
- Identifies vulnerable and marginalized populations and responds appropriately.
- Identifies barriers to palliative care for vulnerable or marginalized populations, including, but not limited to: the homeless, First Nations, Inuit, Métis and urban Indigenous peoples, those who are incarcerated and those living in rural communities.
- Promotes Advance Care Planning, Goals of Care, and Health Care Consent in alignment with Ontario legislation.
- Identifies organizational issues that affect the delivery of palliative care.
- Participates as a member of organizations which advocate for equitable, accessible, safe and quality palliative care.
  - Describes the role of the Canadian Hospice Palliative Care Association, the Ontario Palliative Care Network, and Hospice Palliative Care Ontario in relation to advocating for high quality palliative care for individuals with palliative care needs.

- Describes how changes in legislation could affect individuals with palliative care needs.
- Describes how changes in funding and structure of the health system could affect delivery of palliative care.
- Identifies points of influence in the health system that could advance palliative care issues.
- Describes the moral, ethical and professional issues inherent in health advocacy related to palliative care.
- Advocates for health professionals to participate in palliative care continuing education opportunities.
- Advocates for health professionals to have access to adequate resources to provide palliative care.

Source: Reprinted from Ontario Palliative Care Network (OPCN). The Ontario palliative care competency framework [Internet]. Toronto (ON): OPCN; 2019. Available from: https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNCompetencyFramework.pdf. Reprinted with permissions.

Appendix L: Resources Related to Medical Assistance in Dying

Table 20 provides a list of resources related to Medical Assistance in Dying (MAiD). It is important to note that this is not an exhaustive list of all possible resources available.

Note: Palliative and end-of-life care legislation varies between jurisdictions. Please refer to the resources specific to your jurisdiction for relevant information regarding MAiD.

Table 20: Resources related to Medical Assistance in Dying (MAiD)

ORGANIZATION	TITLE	CONTENTS	WEBSITE
AdvantAge Ontario	Medical Assistance in Dying (MAID): What You Need to Know Now	Access to a toolkit with information on the process of MAiD, legal information, an internal policy checklist, frequently asked questions, case scenarios and a decision tree.	http://www.advantageontario.ca/AAO/Content/Resources/Advantage_Ontario/Medical_Assistanc_%20in_Dying
Belgium Federal Public Services (website available in English and French)		The Belgium Federal Public Service carries out research in policy areas relating to health, food, animals and plants, and the environment. The website contains: ■ laws on patient' rights (www.patientrights.be); and ■ opinion documents published about topics related to MAiD.	https://www.health.belgium.be/en
The Canadian Medical Protective Association (CMPA) (website available in English and French)	Public Policy: What the Legislation on Medical Assistance in Dying Means for Physicians in Canada	Policy response regarding legislation on MAiD for physicians in Canada.	https://www.cmpa-acpm.ca/en/research-policy/public-policy/what-the-legislation-on-medical-assistance-in-dying-means-for-physicians-in-canada

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Canadian Nurses Association (CNA) (website available in English and French)	Medical Assistance in Dying	This webpage contains: ■ online learning modules through NurseOne.ca; ■ the *National Nursing Framework on Medical Assistance in Dying in Canada;* ■ the *CNA Statement on the Passage of Bill C-14*; ■ the Code of Ethics for Registered Nurses; ■ palliative care and end-of-life resources; and ■ CNA presentations and briefs.	https://www.cna-aiic.ca/en/policy-advocacy/palliative-and-end-of-life-care/medical-assistance-in-dying
Canadian Nurses Protective Society (website available in English and French)	Medical Assistance in Dying: What Every Nurse Should Know	Information regarding the implications of Bill C-14 for nurse practitioners and nursing professionals.	https://cnps.ca/MAID
College of Nurses of Ontario (CNO)	Guidance on Nurses' Roles in Medical Assistance in Dying	Document that provides guidance on the roles and accountabilities of nurses related to MAiD.	www.cno.org/globalassets/docs/prac/41056-guidance-on-nurses-roles-in-maid.pdf
The College of Physicians and Surgeons of Ontario	Medical Assistance in Dying	Policy outlining: ■ legal obligations and professional expectations for physicians in relation to MAID; ■ expectations for postgraduate medical trainees; ■ eligibility criteria for MAID; and ■ process map to assist professionals who are managing requests for MAID.	https://www.cpso.on.ca/admin/CPSO/media/Documents/physician/polices-and-guidance/policies/medical-assistance-in-dying.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Dying with Dignity Canada	Dying with Dignity Canada: It's Your Life. It's Your Choice	This website contains: ■ End-of-life patients rights booklet. □ Explains the different options when considering end-of-life care. ■ The *Protect Yourself: Your Rights as a Patient* document. □ Identifies different rights one should know when transitioning through end of life. ■ The *Get the Facts: Bill C-14 and Assisted Dying Law in Canada* document. □ Provides an overview and explanation of Bill C-14.	http://www.dyingwithdignity.ca/know_your_rights
Government of Canada (website available in English and French)	Medical Assistance in Dying	This webpage contains: ■ information on who can provide MAiD and who can help; ■ a list of eligibility criteria; ■ details on how to obtain medical assistance in dying; ■ an outline of provincial and territory variations; and ■ resources to support palliative care and other end-of-life care options.	https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html
Government of Canada, Department of Justice (website available in English and French)	Legislative Background: Medical Assistance in Dying (Bill C-14, as Assented to on June 17, 2016) AND Medical Assistance in Dying: About the Proposed Legislation	This webpage contains: ■ access to legislative background on Bill C-14; ■ eligibility criteria; ■ changes to the criminal code to enable access to MAiD; ■ types of MAiD; ■ protective measures and safeguards in proposed legislation; ■ monitoring and reporting; and; ■ parliamentary process.	http://justice.gc.ca/eng/cj-jp/ad-am/index.html

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Government of Ontario (website available in English and French)	Medical Assistance in Dying and End-of-Life Decisions	This webpage contains: ■ resources for finding someone to help with MAiD; ■ eligibility criteria; ■ facilities that provide MAiD; and ■ information on withdrawing a request.	https://www.ontario.ca/page/medical-assistance-dying-and-end-life-decisions
Kingdom of Belgium Foreign Affairs, Foreign Trade and Development Cooperation (website available in English and French)	Euthanasia Declaration	Form for Belgian citizens to make a euthanasia declaration.	https://diplomatie.belgium.be/en/services/services_abroad/euthanasia_declaration
Ontario Hospital Association (OHA)	End-of-Life Care	This webpage contains current developments with relation to end-of-life care and MAiD. Topics include: ■ background information on Bill C-14; ■ OHA submissions; ■ frequently asked questions on physician-assisted death; ■ interview with coroner indicating their role in MAiD; and ■ case updates.	https://www.oha.com/legislative-and-legal-issues/end-of-life-care
Ontario Ministry of Health and Ontario Ministry of Long-Term Care (website available in English and French)	Medical Assistance in Dying	This webpage contains: ■ links to Bill C-14 (readings and royal assent); ■ link to Bill 84: Medical Assistance in Dying Statue Law Amendment Act; and ■ information on MAiD (definition, eligibility, patient request and assessments, and how to contact Medical Assistance in Dying Care Coordination Service).	http://www.health.gov.on.ca/en/pro/programs/maid/default.aspx

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Parliament of Canada (website available in English and French)	Bill C-14: An Act to Amend the Criminal Code and to Make Related Amendments to other Acts (Medical Assistance in Dying)	Bill C-14 and its amendments.	http://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent
	Carter v. Canada: The Supreme Court of Canada's Decision on Assisted Dying	Document outlining the supreme court of Canada's decision on physician-assisted dying.	https://lop.parl.ca/staticfiles/PublicWebsite/Home/ResearchPublications/BackgroundPapers/PDF/2015-47-e.pdf
The Quality Hospice Palliative Care Coalition of Ontario (HPCO)	The Quality Hospice Palliative Care Coalition of Ontario: Working to Ensure Quality Hospice Palliative Care in all Care Settings from Home to Hospital, Throughout the Province	HPCO was formed to bring together organizations, universities and research institutions in the hospice palliative care field at a provincial level. This webpage contains: ■ hospice palliative care facts; ■ the Provincial Hospice Palliative Care Review Document, which is a tool used to inform regional planning in palliative care across Ontario; and ■ documents on improving the quality of hospice palliative care across Ontario.	http://hpco.ca/qhpcco/
Registered Nurses' Association of Ontario (RNAO)	The End-Of-Life Debate	Cover story published in the March/April 2015 edition of the *Registered Nurse Journal*.	RNAO.ca/resources/rnj/issues/marchapril-2015
	Draft Guidance on Nurses' Roles in Medical Assistance in Dying (College of Nurses of Ontario)	RNAO's review and recommendations on the College of *Nurses of Ontario Nurses' Roles in Medical Assistance in Dying* document.	RNAO.ca/policy/letters/cno-draft-guidance-nurses-roles-medical-assistance-dying
	Medical Assistance in Dying: What Nurses Need to Know	Links to RNAO webinars and slides on MAiD, highlighting legal and regulatory obligations and expectations.	RNAO.ca/events/medical-assistance-dying-what-nurses-need-know
	NP Authority to Prescribe Controlled Substances	Policy letter on authority of nurse practitioners to prescribe controlled substances written to Dr. Eric Hoskin.	RNAO.ca/policy/letters/authority-prescribe-controlled-substances

ORGANIZATION	TITLE	CONTENTS	WEBSITE
St. Michael's Hospital	Patient Care: Medical Assistance in Dying (MAID)	Access to information regarding MAiD for patients.	http://www.stmichaelshospital.com/programs/maid.php
TheWell	Medical Assistacne in Dying (MAID) Resource: Ontario	This webpage contains: ■ a pathway outlining process for provision of MAiD; ■ exploring patient's motivations for requests for MAiD; ■ an assessment of patient eligibility; ■ steps for the provision of MAiD; ■ a documentation checklist; and ■ a list of resources, documents, policy statements and tools for clinicians.	https://thewellhealth.ca/maid/
University of Toronto Joint Centre for Bioethics	Key Considerations for Addressing Interim Requests for a Physician-assisted Death Exemption	Considerations for health providers and organizations in Ontario who receive inquiries and requests for physician assisted death.	http://jcb.utoronto.ca/news/documents/JCB-PAD-Implementation-Task-Force-Key-Considerations.pdf
ARTICLES			
Suva G, Penney T, McPherson CJ. Medical assistance in dying: a scoping review to inform nurses' practice. J Hosp Palliat Nurs. 2019 Feb;21(1):46-53.		■ Scoping review which synthesizes the evidence on nurses' roles and responsibilities in relation to medical assistance in dying and identifies gaps in the literature.	

Appendix M: Supporting Resources

Note: Palliative care and end-of-life care laws vary between jurisdictions. Please refer to the resources specific to your jurisdiction for relevant information regarding palliative care and end-of-life care.

In addition to the resources listed for each recommendation, please see below for supporting resources related to the following:

- advance care planning;
- culture;
- compassion fatigue, stress and resilience;
- death doulas;
- debriefing;
- grief and bereavement;
- palliative and end-of-life care for Indigenous populations;
- recognizing when a person may be in the last days of life or when a person may benefit from palliative care;
- sexual orientation, gender identity and gender expression;
- standards, policy documents, models, guides and frameworks;
- toolkits and information for providing support in palliative care; and
- young adult population.

It is important to note that the following table is not an exhaustive list of all possible resources available.

Table 21: Supporting Resources

ADVANCE CARE PLANNING			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Advance Care Planning	Healthcare Provider Resources	Resources for health providers regarding advance care planning.	http://acpww.ca/resources/healthcare-provider-resources/
Alberta Health Services	Advance Care Planning/Goals of Care	Provides general information about advance care planning and goals of care, as well as e-learning modules for clinicians, non-clinicians and unit clerks.	https://www.albertahealthservices.ca/info/Page9099.aspx
Cancer Care Ontario	Provider tools for advanced care planning and goals of care discussions	An outline and summary of the evidence about health provider tools and/or practices that address advance care planning and goals of care discussions.	https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/31796
Community Legal Education Ontario (website available in English and French)	Power of Attorney for Personal Care	Website that provides a range of information regarding power of attorney for personal care, such as "What is a power of attorney", "What are personal care decisions?" and "Who decides that I am mentally incapable of making decisions about health treatments?"	https://www.cleo.on.ca/en/publications/power
Georgetown University School of Nursing and Health Studies	Communicating End-of-Life Care Wishes with Clinicans and Family	Webpage provides information for patients regarding what end-of-life care is, strategies to talk to health providers and family about end-of-life care, and what a values history is.	https://online.nursing.georgetown.edu/blog/talking-about-end-of-life-care/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Hospice Palliative Care Ontario (HPCO)	Advance Care Planning and Health Care Consent for Health Service Providers	Provides resources and links to webinars on advance care planning and health care consent.	http://www.hpco.ca/acp-hcc-hsp/
	Advance Care Planning and Health Care Consent: Making Your Wishes Known	Videos that explain the importance of making your health care wishes known, the steps of advance care planning and how to make your wishes known.	http://www.hpco.ca/acp
Hospice Waterloo Region	Legacy Activities	Activities that offer an opportunity for families to reflect on events and people that made an impact on their life.	http://www.hospicewaterloo.ca/resources/legacy-activities/
Meaningful Passages	Meaningful Passages	A website that offers resources and information to support a personalized approach to life transitions.	https://www.meaningfulpassages.com/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Ontario Palliative Care Network (OPCN)	Advance Care Planning, Goals of Care, and Treatment Decisions & Informed Consent Frequently Asked Questions (FAQ)	Frequently asked questions by patients and families regarding advance care planning, goals of care and treatment decisions.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocFAQ.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocFAQ-FR.pdf (French)
	Approaches to Goals of Care Discussions	Resource for healthcare providers that offers a framework and content on how to approach discussions regarding goals of care with persons living with a life-limiting illness or a substitute decision maker.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/ApproachesToGoalsOfCare.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/ApproachesToGoalsOfCare-FR.pdf (French)
	Making Decisions About Your Care	Resource for patients and families that explains advance care planning, goals of care and treatment decisions and informed consent.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocPatientResource.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocPatientResource-FR.pdf (French)
	Person-Centred Decision-Making	Resource for healthcare providers that covers goals of care conversations, advance care planning conversations and treatment and informed consent conversations.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocPCDMProviderResource.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNGocPatientResource-FR.pdf (French)

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Speak Up Ontario	Advance Care Planning Workbook: Ontario Edition	A resource for patients and families to become familiar with advance care planning in Ontario, and to help prepare them for when they may not be able to make their own health decisions.	https://www.speakupontario.ca/wp-content/uploads/2018/07/ACP_Ont_workbook_2018_Eng.pdf
	Resources for Health Care Providers	A range of resources for health providers, including e-learning modules, webinars, a substitute decision maker hierarchy, workbook and the Health Care Consent Advance Care Planning Tool Kit.	https://www.speakupontario.ca/resources-for-health-care-providers/
	Part 2: Substitute Decision Makers	Information and resources for substitute decision makers, including what a substitute decision maker is, who can be a witness to a power of attorney for personal care, and what is a substitute decision maker that is a "spouse".	https://www.speakupontario.ca/resource-guide/part-2-substitute-decision-makers/
	Who Will Speak for You?	Contains information for patients and families, health care professionals, community organizations, and educators and researchers about advance care planning. Resources are from across Canada.	http://www.advancecareplanning.ca/
	French language resources	Resources provided in French, such as videos on advance care planning in Ontario and confirming a substitute decision maker in Ontario. Also a link to order additional resources in French.	https://www.speakupontario.ca/resources-for-health-care-providers/?cat=null&keyword=&lang%5B%5D=75#directory-anchor

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Tertiary Palliative Care Unit, Grey Nuns Community Hospital	Legacy Work in Palliative Care: Experiences on the Tertiary Palliative Care Unit	PowerPoint presentation that defines and clarifies Legacy work, aims to explain the role of Legacy work in palliative care, defines considerations when identifying patients who are appropriate for Legacy work, and describes the experiences of patients, families and staff with legacy work.	http://www.palliative.org/NewPC/_pdfs/education/2013%20conference%20materials/Legacy%20Work%20in%20Palliative%20Care%20Best.pdf

CULTURE			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Canadian Hospice Palliative Care Association	Caring for the Terminally Ill: Honoring the Choices of the People	A book created to provide support for Indigenous people and their families who live in rural and remote communities and who are living with life threatening illness.	http://www.chpca.net/media/7514/Caring_for_the_Terminally_Ill.pdf
Canadian Virtual Hospice	LivingMyCulture.ca	A multilingual website that offers stories shared about living with serious illness, end of life and grief.	http://livingmyculture.ca/culture/
Multicultural Mental Health Resource Centre (website available in English and French)	Training Materials	A range of training materials regarding cultural competency.	http://www.multiculturalmentalhealth.ca/training/cultural-competence/cultural-competence-tools-and-guidelines/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
National Aboriginal Health Organization (NAHO)	Cultural Competency and Safety: A Guide for Health Care Administrators, Providers and Educators	Document that provides background on the origins of cultural competency and cultural safety, while also providing information explaining the need for culturally competent and safe care, providing stakeholders in the process and outlining ways to evaluate health care programs and policies.	https://en.unesco.org/interculturaldialogue/resources/249

COMPASSION FATIGUE, STRESS AND RESILIENCE			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
eMentalHealth.ca (website available in English and French)	Resiliency	Resources related to mental health and resiliency.	https://www.ementalhealth.ca/index.php?m=headingInfoSheets&ID=384
Hamilton Health Sciences	Making Time to Grieve	Video explaining a strategy developed by staff on an Oncology and G.I Medicine unit that helps nurses have a chance to grieve after the death of a patient.	https://hhsshare.ca/news/compassion-breaks/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Mayo Clinic	Mayo Clinic Resilient Mind	Digital program designed to build resilience, reduce stress and anxiety, and increase happiness.	https://resilience.mayoclinic.org
The Mindfulness Institute	Mindfulness-Based Stress Reduction (MBSR) Program	Intensive training in mindfulness and cognitive behavioural and self-regulation skills, whereby individuals learn how to facilitate learning, growth, healing, enhance self-care and make positive shifts in attitudes, behaviours and relationships.	http://www.mindfulnessinstitute.ca/mbsr/
Professional Quality of Life Scale	Professional Quality of Life Measure: ProQOL.org	Assessment tool measuring compassion fatigue and compassion satisfaction.	https://proqol.org/ProQol_Test.html
Resilience Research Centre	Tools	Range of research tools that can be adapted to research on resiliency.	http://resilienceresearch.org/resources/tools
Self-compassion.org	Self-Compassion	Program to teach self-compassion skills in daily life.	www.self-compassion.org
ARTICLES AND BOOKS			
Baidoobonso S. Effect of supportive interventions on informal caregivers of people at the end of life: a rapid review. Toronto: Health Quality Ontario; 2014 December. Available from: http://www.hqontario.ca/Portals/0/Documents/evidence/rapid-reviews/eol-supportive-interventions-1411-en.pdf		An analysis to determine the effectiveness of supportive interventions in improving coping and reducing burden and distress for informal caregivers of patients who are at the end of life.	

Lipsky LV. Trauma stewardship: an everyday guide to caring for self while caring for others. San Francisco: Berrett-Koehler; 2010.	Offers the reader strategies to keep from becoming overwhelmed by developing a quality of mindful presence.
Murray, K. Essentials in Hospice and palliative Care: A practical resource for every nurse. Victoria, BC: Life and Death Matters, 2016.	Includes content on self-evaluation for compassion fatigue and strategies for developing self-care (Chapter 8: Caring for YOU!).
Saakvitne KW, Pearlman LA, Abrahamson DJ. Transforming the pain: a workbook on vicarious traumatization. New York: WW Norton; 1996.	A workbook designed to take care of the helper—to help helpers assess, address, and transform their vicarious traumatization.
Stamm B. Secondary traumatic stress: self-care issues for clinicians, researchers, and educators. [place unknown]: The Sidran Press; 1995.	Reflects the state of knowledge about secondary traumatisation.

DEATH DOULAS

ORGANIZATION	TITLE	CONTENTS	WEBSITE
End of Life Doula Association of Canada	End of Life Doula	Information about how to hire a doula and how to become an end-of-life doula.	https://endoflifedoulaassociation.org/
Canadian Integrative Network for Death Education and Alternatives (CINDEA)	Death Midwifery	Information about death midwifery, including what it is and training options to become a death midwife.	http://www.cindea.ca/midwifery.html
Home Hospice Association	Death Doula	Information about death doulas, and links to upcoming certification programs.	https://www.homehospiceassociation.com/be-a-death-doula
	Don't Walk the Journey Alone	Information and support for persons and families, along with professional development training.	https://www.homehospiceassociation.com/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Institute of Traditional Medicine	Contemplative End of life Care	Information about Canada's first contemplative end of life care program, and training opportunities for the program.	http://itmworld.org/ceolc/
International End-of-life Doula Association	INELDA	Information, certification and training for end of life doulas.	https://www.inelda.org/
Soul Passages	Soul Passages	Support for navigating death, loss and transformation.	https://soulpassages.ca/

ARTICLES AND BOOKS	
Baldwin P. Death cafés: death doulas and family communication. Behav Sci (Basel). 2017;7(2):26.	Using the insights provided by interviews from 15 Death Café facilitators, this manuscript discusses the role of the Death Café facilitators as the death doulas of family communication.
Fersko-Weiss H. Caring for the dying: the doula approach to a meaningful death. [place unknown]: Red Wheel/Weiser; 2017.	This book explores how the dying and their families can bring deep meaning and great comfort to the care given at the end of a life.

DEBRIEFING			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
American Heart Association	PEARLS Scripted Debriefing Tool	A cognitive aid that supports educator training and addresses the phases of debriefing, associated objectives and tasks, and sample phrases. It also outlines performance domains and provides three approaches for analyzing clinical or simulated events.	https://www.heart.org/idc/groups/heart-public/@wcm/@hcm/@gwtg/documents/downloadable/ucm_486571.pdf
Canadian Virtual Hospice	Grief	Bereavement debriefing for health providers.	http://www.virtualhospice.ca/default.aspx?goto=en_US-Main+Site+Navigation-Home-For+Professionals-For+Professionals-Quick+Consults-Grief-What+format+and+questions+would+you+use+in+a+bereavement+debriefing+session+for+health+care+staff+after+a+traumatic+death_ (English) http://www.virtualhospice.ca/default.aspx?goto=fr_CA-Main+Site+Navigation-Home-For+Professionals-For+Professionals-Quick+Consults-Grief-What+format+and+questions+would+you+use+in+a+bereavement+debriefing+session+for+health+care+staff+after+a+traumatic+death_ (French)
Debrief 2 Learn	PEARLS Healthcare Debriefing Tool	A cognitive aid that supports educator training and addresses the phases of debriefing, associated objectives and tasks, and sample phrases. It also outlines performance domains and provides three approaches for analyzing clinical or simulated events.	https://debrief2learn.org/pearls-debriefing-tool/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Quality Palliative Care in Long Term Care Alliance (QPC-LTC)	Peer Led Debriefing Toolkit: Guidelines for Promoting Effective Grief Support Among Front Line Staff	A practice and training resource for palliative care programs in long term care that incorporates peer led debriefings in the workplace.	http://www.palliativealliance.ca/assets/files/Alliance_Reources/Org_Change/Peer_Led_Debriefing-_Final.pdf
Royal College of Nursing	Debate: Nurse Debriefing	Information about a debate held regarding nurse debriefing, along with a video of the debate and a report.	https://www.rcn.org.uk/congress/whats-on/nurse-debriefing#about
ARTICLES			
Sawyer T, Eppich W, Brett-Fleegler M, Grant V, Cheng A. More than one way to debrief: a critical review of healthcare simulation debriefing methods. Simul Healthc. 2016 Jun;11(3):209-17.		Review examining the timing, facilitation, conversational structures and process elements used in health-care simulation debriefing.	

GRIEF AND BEREAVEMENT			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
BCGuidelines.ca	Palliative Care for the Patient with Incurable Cancer or Advanced Disease—Part 3: Grief and Bereavement	Information and resources for health providers on grief and bereavement to improve their comfort and skills when dealing with loss due to incurable cancer or advanced disease.	https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-grief-and-bereavement
Canadian Virtual Hospice	MyGrief.ca	Website dedicating to helping people to understand and work through grief.	http://www.mygrief.ca
Center for Loss & Life Transition	Center for Loss and Life Transitions	Dedicated to "companioning" grieving people as they mourn significant transitions and losses that transform their lives.	https://www.centerforloss.com/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Centre for Palliative Care	Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients	Resource for health professionals that provides guidance on how to improve psychosocial and bereavement support to family caregivers of patients who are in palliative care.	https://engonetcpc.blob.core.windows.net/assets/uploads/files/Assets/CPG%20Psychosocial%20bereavement%20suport(1).pdf
BOOKS			
Murray, K. Essentials in Hospice and palliative Care: A practical resource for every nurse. Victoria, BC: Life and Death Matters, 2016.		Explores best practice in supporting the dying person and family through losses, grief and bereavement (Chapter 6: Providing Psychosocial Care).	
Wolfelt AD. Companioning the bereaved: a soulful guide for counselors & caregivers. [place unknown]: Companion Press; 2005 Mar 1. Wolfelt AD. The handbook for companioning the mourner: eleven essential principles. [place unknown]: Companion Press; 2009 Apr 1. Wolfelt AD. The mourner's book of hope. [place unknown]: Companion Press; 2010 Oct 1		A companion of books which examines and redefines the role of the grief counselor and offers guides for caregivers.	

PALLIATIVE AND END-OF-LIFE CARE FOR INDIGENOUS POPULATIONS			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Canadian Hospice Palliative Care Association (CHPCA)	National Inventory of Hospice Palliative Care Resources and Tools for Indigenous Peoples	List of resources and tools for Indigenous people with respect to hospice palliative care.	http://www.chpca.net/media/7712/Inventory_Aboriginal_Resources_2007.pdf (English) http://acsp.net/media/34650/Repertoire-national-des-ressources_soins-palliatifs_premieres-nations-inuits-2007.pdf (French)
Canadian Nurses Association (CNA)	Cultural Competence and Cultural Safety in Nursing Education: A Framework for First Nations, Inuit, and Métis Nursing	The core competencies that serve as foundational structures and processes to support Aboriginal nursing education.	https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/first_nations_framework_e.pdf (English) https://casn.ca/wp-content/uploads/2014/12/FrenchFinalReviewofliterature.pdf (French)
Cancer Care Ontario (website available in English and French)	Indigenous Relationship and Cultural Competency Courses	A list of courses available to enhance knowledge and cultural competence with respect to First Nations Inuit and Métis people.	https://elearning.cancercare.on.ca/course/index.php?categoryid=2
	Palliative Care Toolkit for Indigenous Communities	Includes resources and material for First Nations, Métis and Inuit families and communities to support people with cancer and who have palliative care needs.	https://www.cancercareontario.ca/en/guidelines-advice/treatment-modality/palliative-care/toolkit-aboriginal-communities
Indigenous Cultural Safety (ICS) Learning Series	Indigenous Cultural Safety Collaborative Learning Series	Webinars related to Indigenous cultural safety in health and social services.	http://www.icscollaborative.com/
Lakehead University	Improving End-of-life Care in First Nations Communities	Information about a project to improve end-of-life care in four First Nations communities, including the results of the project, information about the workbook and information about the communities.	http://eolfn.lakeheadu.ca/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Truth and Reconciliation Commission of Canada	Truth and Reconciliation Commission of Canada: Calls to Action	Calls to Action (Health) #22–24 (p. 3) speak to holistic care for Indigenous persons. ▪ **Call to Action #22:** We call upon those who can effect change within the Canadian health-care system to recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients. ▪ **Call to Action #23:** We call upon all levels of government to: □ Increase the number of Aboriginal professionals working in the health-care field. □ Ensure the retention of Aboriginal health providers in Aboriginal communities. □ Provide cultural competency training for all healthcare professionals. ▪ **Call to Action #24:** We call upon medical and nursing schools in Canada to require all students to take a course dealing with Aboriginal health issues, including the history and legacy of residential schools, the United Nations Declaration on the Rights of Indigenous Peoples, Treaties and Aboriginal rights, and Indigenous teachings and practices. This will require skills-based training in intercultural competency, conflict resolution, human rights and anti-racism.	https://nctr.ca/assets/reports/Calls_to_Action_English2.pdf (English) http://publications.gc.ca/collections/collection_2015/trc/IR4-8-2015-fra.pdf (French)

RECOGNIZING WHEN A PERSON MAY BE IN THE LAST DAYS OF LIFE OR WHEN A PERSON MAY BENEFIT FROM PALLIATIVE CARE			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Canadian Hospice Palliative Care Association (CHPCA)	A Caregivers Guide: A Handbook about End-of-life Care	A book written for and dedicated to caregivers who are assisting friends and family during the end-of-life journey.	https://hospicetoronto.ca/PDF/Acaregivershandbook_CHPCA.pdf
Gold Standards Framework (GSF)	Proactive Identification Guidance: The National GSF Centre's Guidance for Clinicians to Support Earlier Identification of Patients Nearing the End of Life Leading to Improved Proactive Person-centred Care	A document aimed to allow for early identification of people nearing the end of their life and who may need additional support.	https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf
National Institute for Health and Care Excellence (NICE)	Care of Dying Adults in the Last Days of Life	Guideline that includes recommendations focused on: (a) recognizing when a person may be in the last days of life; (b) communication; (c) shared decision-making; (d) maintaining hydration; (e) pharmacological interventions; and (f) anticipatory prescribing.	https://www.nice.org.uk/guidance/ng31

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Ontario Palliative Care Network (OPCN)	Tools to Support Earlier Identification for Palliative Care	Document to support health providers and system-level leaders in identifying patients earlier who would benefit from palliative care.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNToolsToSupportEarlierIdentificationForPC.pdf
BOOKS			
Murray, K. Essentials in Hospice and palliative Care: A practical resource for every nurse. Victoria, BC: Life and Death Matters, 2016.		Reviews how to support a person and family in the last days and hours (Chapter 7: Caring in the last Days and Hours).	

SEXUAL ORIENTATION, GENDER IDENTITY AND GENDER EXPRESSION			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Egale Canada Human Rights Trust	Crossing the Rainbow Bridge	A resource that supports end-of-life planning and end-of-life care needs of LGBTQI2S older adults in Ontario.	https://egale.ca/crossing-rainbow-bridge/
Marie Curie	"Hiding Who I Am": The Reality of End-of-life Care for LGBT People	A report that includes stories and experiences of LGBT people with end-of-life care.	https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf
National LGBT Cancer Network	LGBT Palliative Care	Training resources for health providers with respect to LGBT cultural competence.	https://cancer-network.org/cancer-information/cancer-and-the-lgbt-community/lgbt-palliative-care/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Simon Fraser University	LGBT End-of-Life Conversations	Website dedicated to providing knowledge exchange and dialogue for LGBT adults and others.	https://www.sfu.ca/lgbteol.html
	The British Columbia LGBT End-of-life Resource Inventory	A list of LGBT friendly end-of-life resources for older adults.	https://www.sfu.ca/content/dam/sfu/lgbteol/pdf/JUNE%202017%20BC%20inventory.pdf
Spectrum	The Rainbow Pages (resource directory)	Resources from Waterloo-Wellington for LGBTQ+ communities, including links to groups, agencies and professionals who offer services for the local LGBTQ communities.	http://ourspectrum.com/resources/rainbow-directory/

STANDARDS, POLICY DOCUMENTS, MODELS, GUIDES AND FRAMEWORKS			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
BC Centre for Palliative Care	BC Centre for Palliative Care Information	Interactive PDF focusing on interprofessional palliative symptom management. Includes content related to the following: pain; fatigue; pruritus; severe bleeding; constipation; nausea and vomiting; dysphagia; anorexia; dehydration; respiratory congestion; dyspnea; cough; hiccoughs; twitching/myoclonus/ seizures; and delirium.	https://www.bc-cpc.ca/cpc/wp-content/uploads/2018/08/B.C.-Symptom-guidelines-May-2018-Interactive.pdf
	The Public Health Approach to Palliative Care	Overview of the public health approach to palliative care, including conceptual principles, operational levels and essential public health strategies to address a population health problem.	http://bc-cpc.ca/cpc/documents/pdf/Chapter%203-%20A%20Public%20Health%20Approach%20to%20Palliative%20Care.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
BCGuidelines.ca	Palliative Care for the Patient with Incurable Cancer or Advanced Disease— Part 2: Pain and Symptom Management	Guideline for patients 19 years of age and older that outlines strategies to assess and manage pain due to cancer, along with symptoms associated with advanced disease. Key symptom areas addressed include: constipation; delirium; depression; dyspnea; fatigue and weakness; nausea and vomiting; and pain.	https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines/palliative-pain-management
Canadian Hospice Palliative Care Association (CHPCA)	A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice	Document outlining the principles and norms of practice in order to provide quality care to Canadians with a life-limiting illness.	http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf
	The Way Forward National Framework: A Roadmap for an Integrated Palliative Approach to Care	Document that includes best practices for all care settings to implement an integrated palliative approach to care. Also includes other tools, such as discussion documents and innovative international models.	http://hpcintegration.ca/media/60044/TWF-framework-doc-Eng-2015-final-April1.pdf
Canadian Hospice Palliative Care Standards Sub-committee	Canadian Hospice Palliative Care Nursing Standards of Practice	Standards that outline what the public can expect from nurses who have received hospice palliative care certification in Canada.	http://acsp.net/media/367211/chpc_ng.standards.2014.14_july_2014.final.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Canadian Interprofessional Health Collaborative	A National Interprofessional Competency Framework	Document that outlines an approach to the competencies that can guide interprofessional education and collaborative practice for professionals in a variety of contexts.	https://www.cihc.ca/files/CIHC_IPCompetencies_Feb1210.pdf
Canadian Nurses Association (CNA)	Code of Ethics for Registered Nurses	Outlines the ethical values and responsibilities of nurses, along with the code of ethics that is part of the regulatory process to serve and protect the public.	https://www.cna-aiic.ca/~/media/cna/page-content/pdf-en/code-of-ethics-2017-edition-secure-interactive (English) https://www.cna-aiic.ca/html/fr/Code-de-deontologie-Edition-2017/files/assets/basic-html/page-1.html# (French)
Canadian Nurses Association (CNA), the Canadian Hospice Palliative Care Association (CHPCA) and the Canadian Hospice Palliative Care Nurses Group (CHPC-NG)	Joint Position Statement: The Palliative Approach to Care and the Role of the Nurse	Position statement written by the Canadian Nurses Association, the Canadian Hospice Palliative Care Association and the Canadian Hospice Palliative Care Nurses Group in support of a palliative approach to care.	https://www.cna-aiic.ca/-/media/cna/page-content/pdf-en/the-palliative-approach-to-care-and-the-role-of-the-nurse_e.pdf?la=en&hash=E0D799ADB76660EE15D00A7203F862522A2776E8 (English) https://www.cna-aiic.ca/-/media/cna/page-content/pdf-fr/lapproche-palliative-des-soins-et-role-des-infirmieres_f.pdf?la=fr&hash=2C7D91767BBC21A7C06F43AB411C3F11511962F3 (French)
College and Association of Registered Nurses of Alberta	Practice Standards for Regulated Members	Practice standards for nurses (i.e., registered nurses, graduate nurses, certified graduate nurses, nurse practitioners and graduate nurse practitioners) in Alberta.	http://www.nurses.ab.ca/content/dam/carna/pdfs/DocumentList/Standards/PracticeStandards_Jan2013.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Gold Standards Framework (GSF)	The God Standards Framework	National training and coordinating centre in the United Kingdom for all GSF programmes, enabling generalist front-line staff to provide a gold standard of care for people nearing the end of life.	http://www.goldstandardsframework.org.uk/
Government of Canada	Framework on Palliative Care in Canada	Includes resources and information with respect to the palliative care framework in Canada, including what it is, who is responsible for palliative care, and what the purpose of the framework is.	https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html (English) https://www.canada.ca/fr/sante-canada/services/systeme-soins-sante/rapports-publications/soins-palliatifs/cadre-soins-palliatifs-canada.html (French)
Government of Ontario	Health Care Consent Act	Link to the health care consent act established in 1996.	https://www.ontario.ca/laws/statute/96h02 (English) https://www.ontario.ca/laws/statute/96h02 (French)
Health Quality Ontario (HQO) (website available in English and French)	Palliative Care: Care for Adults with a Progressive, Life-Limiting Illness	Quality standard produced by HQO for palliative care.	http://www.hqontario.ca/Evidence-to-Improve-Care/Quality-Standards/View-all-Quality-Standards/Palliative-Care/About
Institute for Clinical Systems Improvement	Health Care Guideline—Palliative Care for Adults	Guideline for primary and speciality care providers to help them identify and care for adults with a serious illness that may be life-limiting, life-threatening, chronic or progressive.	https://www.icsi.org/wp-content/uploads/2019/01/PalliativeCare.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
National Institute for Health and Care Excellence (NICE)	Care of Dying Adults in the Last Days of Life	Guideline that includes recommendations focused on: (a) recognizing when a person may be in the last days of life; (b) communication; (c) shared decision-making; (d) maintaining hydration; (e) pharmacological interventions; and (f) anticipatory prescribing.	https://www.nice.org.uk/guidance/ng31
	Palliative Care for Adults: Strong Opioids for Pain Relief	Guidance for safe and effective prescribing of opioids for adults who require pain relief due to advanced and progressive disease.	https://www.nice.org.uk/guidance/cg140
The Ontario Health Technology Advisory Committee	End-of-Life Health Care in Ontario: OHTAC Recommendation	Document outlining the conclusions from a mega-analysis providing information about: determinants of place of death, patient care planning discussions, end-of-life education, team based model of care, cardiopulmonary resuscitation, supportive interventions for informal caregivers and cost-effectiveness analyses.	http://www.hqontario.ca/Portals/0/Documents/evidence/reports/recommendation-eol-1411-en.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Ontario Ministry of Health and Ontario Ministry of Long-Term Care	Advancing High Quality, High Value Palliative Care in Ontario: A Declaration of Partnership and Commitment to Action	A plan and vision for palliative care in Ontario in order to improve care for people in Ontario at the end of their life.	http://health.gov.on.ca/en/public/programs/ltc/docs/palliative%20care_report.pdf
	Patients First: Action Plan for Health Care	Highlights the four key objectives for the action plan (access, connect, inform and protect) and provides resources and additional information about each objective.	http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/ (English) http://www.health.gov.on.ca/fr/ms/ecfa/healthy_change/ (French)
Ontario Palliative Care Network (OPCN)	Ontario Palliative Care Network Action Plan 1: 2017–2020	A workplan to guide how partners of the Ontario Palliative Care Network will collaborate to improve availability of and access to equitable and sustainable palliative care services.	https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNActionPlan1.pdf (English) https://www.ontariopalliativecarenetwork.ca/sites/opcn/files/OPCNActionPlanFR.pdf (French)
	Palliative Care Health Services Delivery Framework – Focus Area 1: Adults Receiving Care in Community Settings	Palliative care health services delivery framework recommendations for a model of care to improve palliative care in Ontario.	https://www.ontariopalliativecarenetwork.ca/en/healthservicesdeliveryframework (English) https://www.ontariopalliativecarenetwork.ca/fr/etablissementcadreprestationsoinssante (French)
Palliative Care Australia	National Palliative Care Standards, Fifth Edition	Standards developed for specialist palliative care services to support delivery of quality palliative care to persons, families and caregivers.	http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-National-Standards-2018_web-3.pdf

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Quality End-of-life Care Coalition of Canada	Blueprint for Action 2010 to 2020	A report that summarizes the goals, objectives, progress to date, current knowledge, issues and gaps that the Quality End-of-Life Care Coalition of Canada outlined in their blueprint in 2000.	http://www.qelccc.ca/media/3743/blueprint_for_action_2010_to_2020_april_2010.pdf (English) http://www.csfvq.ca/media/3908/fre_progress_report_2010.pdf (French)
The Way Forward (website available in English and French)	The National Framework: A Roadmap for an Integrated Palliative Approach to Care	A guide for healthcare professionals, health system leaders, program planners and others who adopt an integrated palliative care approach.	http://hpcintegration.ca/resources/the-national-framework.aspx
World Health Organization (WHO)	Palliative Care: Symptom Management and End-of-life Care	Guideline that covers the management of symptoms during acute or chronic illness, including information for the patient, family and community caregiver to provide care at home.	http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf?ua=1 (English) https://www.who.int/hiv/pub/imai/imai_palliative_2008_fr.pdf?ua=1 (French)

TOOLKITS AND RESOURCES FOR PROVIDING SUPPORT IN PALLIATIVE CARE			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
American Medical Association (AMA)	An Ethical Force Program Consensus Report: Improving Communication – Improving Care	Report that outlines expectations for ethical actions of health care organizations to promote patient-centered communication.	https://accrualnet.cancer.gov/sites/accrualnet.cancer.gov/files/conversation_files/pcc-consensus-report.pdf
C. Elizabeth Dougherty Consulting	Supporting Children, Youth and Adults Facing Serious Illness, Uncertainty and Loss	Website for Elizabeth's services, which include individual, family and group counselling.	https://cedoughertyconsulting.org/
Canadian Association of Psychosocial Oncology	Canadian Association of Psychosocial Oncology	Resources for patients and practitioners, as well as professional development information regarding psychosocial oncology.	https://www.capo.ca/
Canadian Hospice Palliative Care Association	Guiding Family Caregivers of People at the End of Life: A Handbook	Information and guidance for volunteers who will be supporting family caregivers of people at the end of life in helping them care for themselves.	http://www.chpca.net/media/544599/caregiver_guide_handbook_english_-_may_2016-en.pdf (English) http://acsp.net/media/614998/manuel_pour_guides_des_proches_aidants_aug_31_2016.pdf (French)
	Directory of Services	Online directory to provide information on availability of hospice palliative care services across Canada.	http://www.chpca.net/family-caregivers/directory-of-services.aspx (English) http://acsp.net/adiants-naturels/repertoire.aspx (French)

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Canadian Virtual Hospice (website available in English and French)	Canadian Virtual Hospice	Information and support on palliative care, end-of-life care, loss and grief.	http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
Central Hospice Palliative Care Network	Square of Care	Describes six steps that are essential in the process of providing care: assessment, information sharing, decision making, care planning, care delivery and confirmation.	http://www.centralhpcnetwork.ca/hpc/HPC_docs/formsref/Square%20of%20Care.pdf
Dignity in Care (website available in English and French)	Dignity in care	Information, support and tools to promote compassion and respect in health care.	http://www.dignityincare.ca/en/
Dying with Dignity Canada	Dying with Dignity Canada	Support and resources for persons, families and providers.	http://www.dyingwithdignity.ca/
Government of Alberta	MyHealth.Alberta.ca	Health information and tools on palliative and end-of-life care.	https://myhealth.alberta.ca/palliative-care
Life & Death Matters	Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse Integrating a Palliative Approach: Essentials for Personal Support Workers	Comprehensive resource packages for nurses and personal support workers learning how to provide palliative care, includes textbook, workbook, podcasts, videos, and instructor resources (including PowerPoint presentations).	https://www.lifeanddeathmatters.ca/

ORGANIZATION	TITLE	CONTENTS	WEBSITE
Ontario Ministry of Health and Ontario Ministry of Long-Term Care (website available in English and French)	Palliative and End-Of-Life Care	Includes a roundtable provincial report on palliative and end-of-life care in Ontario and a roadmap to strengthen home and community care for patients.	http://www.health.gov.on.ca/en/public/programs/palliative/
Ontario Palliative Care Network Toolkit	Palliative Care Toolkit	International best-practice tools for primary care providers who deliver palliative care.	https://www.ontariopalliativecarenetwork.ca/en/node/31896
Palliative Alliance	Quality Palliative Care in Long Term Care: Tools and Resources for Organizational Change	Description of a five-year comparative case study that involved four long term care homes in Ontario. Includes information about the outcomes of the research, and a toolkit that was developed.	http://www.palliativealliance.ca/
Palliative Care Innovation	Palliative Care Innovation	Tools related to palliative care.	https://www.palliativecareinnovation.com/4-tools
Registered Nurses' Association of Ontario (RNAO)	Long-Term Care Best Practices Toolkit, 2nd ed.	Resources for end-of-life care in long term care.	http://ltctoolkit.rnao.ca/clinical-topics/end-of-life-care
South West Local Health Integration Network (website available in English and French)	eHealth and Technology	Priority initiatives, past initiatives, plan of action, eHealth tools and technologies related to eHealth and Technology.	http://www.southwestlhin.on.ca/goalsandachievements/Programs/eHealth.aspx

YOUNG ADULT POPULATION			
ORGANIZATION	**TITLE**	**CONTENTS**	**WEBSITE**
Canadian Virtual Hospice	Livingoutloud.life	A webspace created by young adults and teens to break the silence on living with advanced illness. Includes stories and information about relationships, sex and fertility, self, decisions and daily life.	http://livingoutloud.life
National Council for Palliative Care	Difficult Conversations: Making it Easier to Talk about End of Life Issues with Young Adults with Life Limiting Conditions	A guide to support professionals improve the quality of life of young people and their families. It provides information on how to improve the skill of having difficult conversations with young adults who have life-limiting conditions.	http://www.virtualhospice.ca/Assets/Difficult_Conversations_for_Young_Adults_Final_PDF_20151222122927.pdf

ARTICLES AND BOOKS	
Fernandez C, Fraser GA, Freeman C, Grunfeld E, Gupta A, Mery LS et al. Principles and recommendations for the provision of healthcare in Canada to adolescent and young adult–aged cancer patients and survivors. J Adolesc Young Adult Oncol. 2011 Apr;1(1):53-9.	Outlines six broad recommendations from The Canadian Task Force on Adolescents and Young Adults with Cancer. The recommendations highlight the need for age-appropriate psychosocial, survivorship, palliative, and medical care as well as research to redress inequities in the care provided to both younger and older cancer patients.
Grinyer A. Palliative and end of life care for children and young people: home, hospice, hospital. [place unknown]: John Wiley & Sons; 2011 Dec 21.	A resource book on palliative and end-of-life care for children and young adults with cancer and other life limiting illnesses.

Pritchard S, Cuvelier G, Harlos M, Barr R. Palliative care in adolescents and young adults with cancer. Cancer. 2011 May 15;117(S10):2323-8.	The purpose of this review is to identify the needs of the adolescent and young adult population with cancer and to discuss potential barriers and solutions to improvement of care in the context of palliation and symptom management.
Rosenberg AR, Wolfe J. Palliative care for adolescents and young adults with cancer. Clin Oncol Adolesc Young Adults. 2013;3:41-8.	This review describes the scope, benefits, and challenges of palliative care for adolescents and young adult oncology patients.
Tutelman PR, Drake EK, Urquhart R. "It could have been me": an interpretive phenomenological analysis of health care providers' experiences caring for adolescents and young adults with terminal cancer. J Adolesc Young Adult Oncol. 2019 Jun; https://doi.org/10.1089/jayao.2019.0015.	The purpose of the study was to understand health-care providers' experiences caring for adolescents and young adults with terminal cancer.

Appendix N: Description of the *Toolkit*

BPGs can only be successfully implemented if planning, resources, and organizational and administrative supports are adequate, and if there is appropriate facilitation. To encourage successful implementation, an RNAO expert panel of nurses, researchers and administrators has developed the *Toolkit: Implementation of Best Practice Guidelines* (2012). The *Toolkit* is based on available evidence, theoretical perspectives and consensus. We recommend the *Toolkit* for guiding the implementation of any clinical or healthy work environment BPG in a health organization.

The *Toolkit* provides step-by-step directions for the individuals and groups involved in planning, coordinating and facilitating BPG implementation. These steps reflect a process that is dynamic and iterative rather than linear. Therefore, at each phase, preparation for the next phases and reflection on the previous phase is essential. Specifically, the *Toolkit* addresses the following key steps, as illustrated in the Knowledge-to-Action Framework (119):

1. Identify the problem: identify, review and select knowledge (e.g., BPG).
2. Adapt knowledge to the local context:
    a. assess barriers and facilitators to knowledge use; and
    b. identify resources.
3. Select, tailor and implement interventions.
4. Monitor knowledge use.
5. Evaluate outcomes.
6. Sustain knowledge use.

Implementing BPGs to effect successful practice changes and positive clinical impact is a complex undertaking. The *Toolkit* is one key resource for managing this process. It can be downloaded at www.RNAO.ca/bpg/resources/toolkit-implementation-best-practice-guidelines-second-edition

Endorsements

Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs

CHPC Nurses Group

October 25, 2019

Dr. Doris Grinspun, RN, MSN, PhD, LLD (hon), Dr (hc), FAAN, O.NT.
Chief Executive Officer
Registered Nurses' Association of Ontario (RNAO)
158 Pearl Street, Toronto, Ontario M5H 1L3

Dear Dr. Grinspun,

The Canadian Hospice Palliative Care Nurses Group is pleased to offer our support for and endorsement of the second edition of RNAO's best practice guideline – A Palliative Approach to Care in the Last 12 Months of Life.

Aligning with the Canadian Hospice Palliative Care Nursing Standards of Practice, the RNAO guideline provides strong evidence-based guidance and practice information for the health team, supporting care in the last 12 months of life. Given the extensive work being done across the country related to palliative care, the release of this document is timely and highlights the pivotal role that nurses have in nursing and leadership roles to support and implement this national work in collaboration with other key stakeholders.

On behalf of the Canadian Hospice Palliative Care Nurses Group, thank you for the opportunity of review, feedback and endorsement of this document.

Sincerely,

Jeanne Weis MN, RN, LPN, CHPCN (c)
President
Canadian Hospice Palliative Care Nurses Group

Sharon Baxter, MSW
Executive Director
Canadian Hospice Palliative Care Association
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Charitable Registration Number/Numéro d'organisme de bienfaisance : 13760 4195 RR0001

Pallium Canada

January 24, 2019

Doris Grinspun, RN, MSN, PhD, LLD(hon), O.ONT
Chief Executive Officer
Registered Nurses' Association of Ontario (RNAO)
158 Pearl St.
Toronto, ON M5H 1L3

Dear Dr. Grinspun,

Pallium Canada is pleased to offer its support and endorsement of the Registered Nurses' Association of Ontario's (RNAO) best practice guideline *Palliative approach to care in the last 12 months of life*. We appreciate RNAO's stakeholder review process and recognizing Pallium's subject matter expertise in providing feedback on the development of this document.

This guideline will be an invaluable resource for nurses and other members of inter-professional teams who are working with patients with chronic or life-limiting illnesses. What makes this guideline particularly powerful is its emphasis on a holistic approach to care, recognizing the importance of an inter-professional team providing palliative care, which includes health care professionals as well as unregulated care providers and volunteers.

For over 18 years, Pallium Canada has been strengthening hospital, home, and community-based palliative care through education and support to health care professionals and family/neighbour carers so that every Canadian who requires palliative care will receive it early, effectively, and compassionately. Our Learning Essential Approaches to Palliative Care (LEAP) courses, tools, and resources are designed for an inter-professional team and focus on enhancing teamwork and increasing collaboration among health care providers across different settings.

We here at Pallium Canada are looking forward to a day when high quality palliative care is available to all Canadians, and RNAO's efforts to provide evidence-informed best practice recommendations for members of an inter-professional team to better support those in the last 12 months of life will help bring us all closer to reaching this goal.

Kind regards,

Jeffrey B. Moat
Chief Executive Officer

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INTERNATIONAL
AFFAIRS & BEST PRACTICE
GUIDELINES

TRANSFORMING
NURSING THROUGH
KNOWLEDGE

Best Practice Guideline

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RNAO

Registered Nurses' Association of Ontario
L'Association des infirmières et infirmiers autorisés de l'Ontario

Ontario