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Practice Guidelines

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End-of-life Care During the Last Days and Hours

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

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Greetings from Doris Grinspun,

Executive Director Registered Nurses' Association of Ontario

It is with great excitement that the Registered Nurses' Association of Ontario (RNAO) presents this guideline, *End-of-life Care During the Last Days and Hours*, to the health-care community. Evidence-based practice supports excellence in service that nurses are committed to delivering in day-to-day practice. The RNAO is therefore delighted to provide this key resource to you.

The RNAO offers its heartfelt thanks to the many individuals and institutions who make our vision for Nursing Best Practice Guidelines (BPGs) a reality: The government of Ontario for recognizing our ability to lead the program, and for providing multi-year funding; Irmajean Bajnok, Director, RNAO International Affairs and Best Practice Guidelines (IABPG) Programs and Centre for Professional Nursing Excellence, for her expertise and leadership in advancing the production of the BPGs; each and every Team Leader involved, and for this BPG in particular – Christine McPherson – for her superb stewardship, commitment and expertise. Thanks also to Frederick Go, RNAO's IABPG Program Manager, for his intense work to see that this BPG moved from concept to reality. Special thanks are also extended to the BPG Panel – we respect and value your expertise and volunteer work. To all, we could not have done this without you!

The nursing community, with its commitment to and passion for excellence in nursing care, has provided the knowledge and countless hours essential to the development, implementation, evaluation and revision of each guideline. Employers have responded enthusiastically by nominating best practice champions, implementing and evaluating the guidelines and working toward a culture of evidence-based practice.

Successful uptake of these guidelines requires a concerted effort from nurse clinicians and their health-care colleagues from other disciplines, and from nurse educators in academic and practice settings and employers. After lodging these guidelines into their minds and hearts, knowledgeable and skillful nurses and nursing students need healthy and supportive work environments to help bring these guidelines into practice actions.

We ask that you share this guideline with members of your interprofessional team, as there is much to learn from one another. Together, we can ensure that the public receives the best possible care each and every time they come in contact with us. Let's make **them** the real winners in this important effort!

Doris Grinspun, RN, MSN, PhD, LLD(Hon), O.ONT.
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How To Use this Document

This nursing best practice guideline is a comprehensive document, which provides resources necessary for the support of evidence-based nursing practice. The document must be reviewed and applied, based on the specific needs of the organization or practice setting/environment, as well as the needs and wishes of the client. This guideline should not be applied in a "cookbook" fashion, but rather as a tool to enhance decision-making in the provision of individualized care. In addition, the guideline provides an overview of appropriate structures and supports necessary for the provision of best possible care.

Nurses, other health-care professionals and administrators who lead and facilitate practice changes will find this document invaluable for the development of policies, procedures, protocols, educational programs, and assessment and documentation tools. It is recommended that this nursing best practice guideline be used as a resource tool. Nurses providing direct care will benefit from reviewing the recommendations, the evidence in support of the recommendations and the process that was used to develop the guidelines. However, it is highly recommended that practice settings/environments adapt these guidelines in formats that would be user-friendly for daily use. This guideline has some suggested formats for local adaptation and tailoring.

Organizations wishing to use the guideline may do so in a number of ways:

a) Assess current nursing and health-care practices using the recommendations in the guideline.
b) Identify recommendations that will address identified needs or gaps in services.
c) Develop a plan to implement the recommendations systematically, using associated tools and resources.

The Registered Nurses' Association of Ontario is interested in hearing how you have implemented this guideline. Please contact us to share your story. Implementation resources will be made available at our website (www.rnao.org) to assist individuals and organizations in implementing best practice guidelines.

Summary of Recommendations

Practice Recommendations for Assessment at the End of Life

	RECOMMENDATION	Level of Evidence
1.1	Nurses identify individuals who are in the last days and hours of life.	IIa–IV
1.1.1	Use clinical expertise, disease specific indicators and validated tools to identify these individuals.	
1.1.2	Understand the end-of-life trajectories.	
1.2	Nurses understand the common signs and symptoms present during the last days and hours of life.	IIb–IV
1.2.1	Common signs of imminent death, may include, but are not limited to: ▪ progressive weakness; ▪ bedbound state; ▪ sleeping much of the time; ▪ decreased intake of food and fluid; ▪ darkened and/or decreased urine output; ▪ difficulty swallowing (dysphagia); ▪ delirium not related to reversible causes; ▪ decreased level of consciousness not related to other causes; ▪ noisy respiration/ excessive respiratory tract secretion; ▪ change in breathing pattern (Cheyne-Stokes respiration, periods of apnea); and ▪ mottling and cooling extremities.	
1.3	Nurses complete a comprehensive, holistic assessment of individuals and their families based on the Canadian Hospice Palliative Care Association Domains of Care, which include the following: ▪ disease management; ▪ physical; ▪ psychological; ▪ spiritual; ▪ social; ▪ practical; ▪ end-of-life care/ death management; and ▪ loss, grief.	IIb–IV*
1.3.1	Include information from multiple sources to complete an assessment. These may include proxy sources such as the family and other health-care providers.	
1.3.2	Use evidence-informed and validated symptom assessment and screening tools when available and relevant.	
1.3.3	Reassess individuals and families on a regular basis to identify outcomes of care and changes in care needs.	
1.3.4	Communicate assessments to the interprofessional team.	
1.3.5	Document assessments and outcomes.	

1.4	Nurses: ▪ reflect on and are aware of their own attitudes and feelings about death; ▪ assess individuals' preferences for information; ▪ understand and apply the basic principles of communication in end-of-life care; ▪ communicate assessment findings to individuals (if possible and desired) and the family on an ongoing basis; ▪ educate the family about the signs and symptoms of the last days and hours of life, with attention to their: faith and spiritual practices; age-specific needs; developmental needs; cultural needs; and ▪ evaluate the family's comprehension of what is occurring during this phase.	III–IV

Practice Recommendations for Decision Support at the End of Life

2.1	Nurses recognize and respond to factors that influence individuals and their families' involvement in decision-making.	Ib, IV, IV*
2.2	Nurses support individuals and families to make informed decisions that are consistent with their beliefs, values and preferences in the last days and hours of life.	Ia – IV*

Practice Recommendations for Care and Management at the End of Life

3.1	Nurses are knowledgeable about pain and symptom management interventions to enable individualized care planning.	III–IV
3.2	Nurses advocate for and implement individualized pharmacologic and non-pharmacologic care strategies.	Ia–IV
3.3	Nurses educate and share information with individuals and their families regarding: ▪ reconciliation of medications to meet the individual's current needs and goals of care; ▪ routes and administration of medications; ▪ potential symptoms; ▪ physical signs of impending death; ▪ vigil practices; ▪ self care strategies; ▪ identification of a contact plan for family when death has occurred; and ▪ care of the body after death.	Ib–III
3.4	Nurses use effective communication to facilitate end of life discussions related to: ▪ cultural and spiritual values, beliefs and practices; ▪ emotions and fears; ▪ past experiences with death and loss; ▪ clarifying goals of care; ▪ family preference related to direct care involvement; ▪ practical needs; ▪ informational needs; ▪ supportive care needs; ▪ loss and grief; and ▪ bereavement planning.	III

Education Recommendations

4.1	Entry to practice nursing programs and post-registration education incorporate specialized end-of-life care content including: ▪ dying as a normal process including the social and cultural context of death and dying, dying trajectories and signs of impending death; ▪ care of the family (including caregiver); ▪ grief, bereavement and mourning; ▪ principles and models of palliative care; ▪ assessment and management of pain and other symptoms (including pharmacologic and non-pharmacologic approaches); ▪ suffering and spiritual/existential issues and care; ▪ decision-making and advance care planning; ▪ ethical issues; ▪ effective and compassionate communication; ▪ advocacy and therapeutic relationship-building ; ▪ interprofessional practice and competencies; ▪ self-care for nurses, including coping strategies and self-exploration of death and dying; ▪ end-of-life issues in mental health, homelessness and the incarcerated; ▪ the roles of grief and bereavement educators, clergy, spiritual leaders and funeral directors; and ▪ knowledge of relevant legislation.	Ia–III
4.2	Successful education in end-of-life care includes specific attention to the structure and process of learning activities and incorporates: ▪ small group learning; ▪ dyadic and experiential learning approaches; ▪ integration and consolidation of theory and practice; ▪ opportunities to practice the skills and competencies acquired; ▪ constructive feedback and/or reflection on acquired knowledge, skills and competencies; and ▪ contact with knowledgeable and supportive clinical supervisors and mentors.	Ib–III

Organization & Policy Recommendations

5.1	Models of care delivery support the nurse, individual and family relationship.	III–IV
5.2	Organizations recognize that nurses' well-being is a critical component of quality end-of-life care and adopt responsive strategies.	III–IV
5.3	Organizations providing end-of-life care demonstrate evidence of a philosophy of palliative care based on the Canadian Hospice Palliative Care Association's *The Model to Guide Hospice Palliative Care*.	III–IV
5.4	Nursing best practice guidelines can be successfully implemented only when there are adequate planning, resources, organizational and administrative supports, as well as appropriate facilitation. Organizations may wish to develop a plan for implementation that includes: ▪ An assessment of organizational readiness and barriers to implementation ▪ Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process. ▪ Dedication of a qualified individual to provide the support needed for the education and implementation process. ▪ Ongoing opportunities for discussion and education to reinforce the importance of best practices. ▪ Opportunities for reflection on personal and organizational experience in implementing guidelines. In this regard, a panel of nurses, researchers and administrators developed the *Toolkit: Implementation of Clinical Practice Guideline (2002)* based on available evidence, theoretical perspectives and consensus. The Toolkit is recommended for guiding the implementation of the RNAO guideline *End-of-life Care During the Last Days and Hours.*	IV

Interpretation of Evidence

Evidence to support nursing care for individuals at the end of life and their family members is considered with respect to its type, quality and level. Randomized control trials (RCTs) are traditionally considered the "gold standard" of evidence to support the effectiveness of interventions and to guide practice. As such, RCTs have become the benchmark for the establishment of a hierarchy of levels of evidence against which all other ways of knowing are of lesser value. Since RCTs are not always possible to conduct, particularly in end-of-life care, nurses must look toward evidence from other research, such as quasi-experimental and non-experimental quantitative study designs to inform their practice.

In "grading" the evidence to support the recommendations in this guideline, the developers' recognize that there are multiple ways of knowing and understanding that can contribute to the evidence, not only with respect to effectiveness but also the feasibility and appropriateness of interventions, for example, observational studies, qualitative investigations and clinical expertise can provide valuable insights into practices from client and clinician perspectives. All of these approaches contribute to the evidence regarding provision of quality end-of-life care.

In rating the evidence, the developers are mindful that the criterion used varies depending on the research purpose and question. The grading criterion for examining the effectiveness of interventions is not suited to questions regarding prognosis. Therefore, two separate grading criteria were used to evaluate the evidence for this best practice guideline.

Types of Evidence

Type	Therapy/Prevention/Etiology/Harm	Prognosis
Ia	Evidence obtained from systematic review and meta-analysis of randomized controlled trials.	Evidence obtained from systematic review of inception cohort studies.
Ib	Evidence obtained from at least one well-designed randomized controlled trial.	Evidence obtained from at least one well-designed inception cohort study with follow-up.
IIa	Evidence obtained from at least one well-designed controlled study without randomization.	Evidence obtained from systematic review of retrospective cohort studies or untreated control groups in randomized controlled trials.
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study.	Evidence obtained from at least one well-designed retrospective cohort study or follow-up of untreated control patients in a randomized controlled trial.
III	Evidence obtained from at least one well-designed non-experimental quantitative study (i.e. comparative or correlational) or qualitative study.	Evidence obtained from at least one well-designed non-experimental quantitative study (i.e. case-series, case-control studies, cohort studies and historically controlled studies).
IV	Evidence obtained from expert committee reports or opinions, and/or clinical experiences of respected authorities.	Evidence obtained from expert committee reports or opinions, and/or clinical experiences of respected authorities.
IV*	Evidence obtained from other clinical practice guidelines.	Evidence obtained from other clinical practice guidelines.

Adapted from: Centre for Evidence-Based Medicine. *CEBM levels of evidence*. Oxford, UK: Oxford Centre for Evidence-Based Medicine, University of Oxford. Retrieved June 10, 2011, from http://www.cebm.net/index.aspx?o=5653

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Declarations of interest and confidentiality were made by all members of the guideline development panel. Further details are available from the Registered Nurses' Association of Ontario.

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Stakeholders representing diverse perspectives were solicited for their feedback and the Registered Nurses' Association of Ontario would like to acknowledge the following for their contribution in reviewing this Nursing Best Practice Guideline:

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Introduction

Background Context

Care of individuals who are dying is an integral part of health care. In Canada, chronic disease is the predominant cause of death, with deaths from cancer now exceeding deaths from cardiovascular diseases. These two diseases now account for almost 60% of all deaths in Canada (Statistics Canada, 2007a; Statistics Canada, 2007b). The prevalence of chronic disease in older adults, combined with an aging population, means that providing high-quality care specific to the needs of individuals at the end of life and their families is imperative. In her report entitled *Raising the Bar*, Carstairs (2010) highlights issues that face stakeholders in building capacity to ensure that end-of-life care is accessible to all Canadians. In this report, with the exception of sudden death, individuals (i.e. a person with life-limiting illness and/or their family members) with end-stage disease, frailty or terminal illness are identified as potentially benefiting from end-of-life care.

What are Palliative, Hospice and End-of-life care?

Palliative care is both a philosophy and an approach to care. Although the terms palliative care, hospice care and end-of-life care are often used interchangeably, there are differences among them. As Figure 1 illustrates, palliative care (identified as hospice palliative care in the figure) is not restricted to care during the last months or days of life. Rather, palliative care can be used in conjunction with curative treatments. Hospice care, on the other hand, usually refers to the last months of life and brings with it an association with the place of care as a specialized facility. End-of-life care more accurately reflects the emphasis on the last days and hours of life (Figure 1). Therefore, throughout this guideline we have chosen to use the term end-of-life care, since this is the focus of this guideline. Regardless of the term, a palliative approach to the care of people facing life-limiting disease is the common philosophical basis. The Canadian Hospice Palliative Care Association (CHPCA) defines hospice palliative care as an approach to care that aims to:

> "Relieve suffering and improve the quality of living and dying. Such care approach strives to help patients and families: 1) Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; 2) Prepare for and manage self-determined life closure and the dying process; and 3) Cope with loss and grief during the illness and bereavement" (Ferris et al., 2002, p. 17)

The World Health Organization's (WHO) definition of palliative care closely aligns with the CHPCA's definition of hospice palliative care. WHO (2002) defines palliative care as an approach to care that aims to:

> "Improve the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." (p.14).

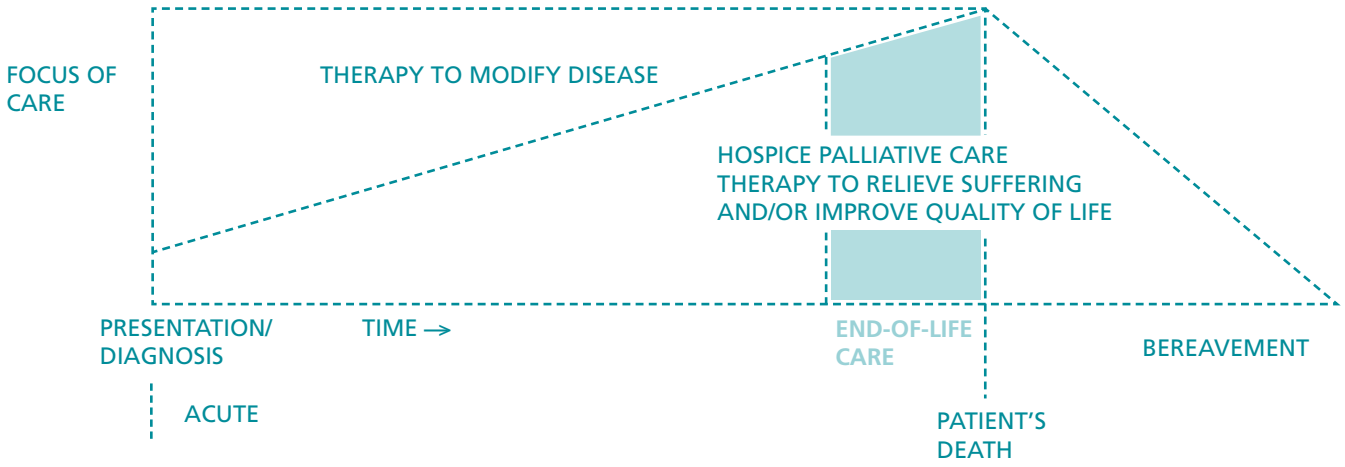

Figure 1. The role of hospice palliative care during illness

Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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End-of-life Care

Within the palliative care philosophy, death is viewed as a normal process; thus, the aim of palliative care is to neither hasten nor postpone death. End-of-life care (CHPCA, 2002):

- Encompasses care of the whole person, including his/her physical, psychological, social, spiritual and practical needs.
- Ensures that care is respectful of human dignity.
- Supports meaningful living as defined by the individual.
- Tailors care planning to meet the individual's goals of care.
- Recognizes the individual with life-limiting disease and his/her family as the unit of care.
- Supports the family to cope with loss and grief during the illness and bereavement periods.
- Respects the individual's personal, cultural and religious values, beliefs and practices in the provision of care.
- Values ethical principles of autonomy, beneficence, non-maleficence, justice, truthfulness and confidentiality.
- Recognizes the individual as autonomous, who has a right to end-of-life care and to make decisions regarding his/her care to the degree he/she desires.
- Recognizes the importance of a collaborative interprofessional team approach to care, and also recognizes the efforts of non-health-care professionals (e.g. volunteers, faith leaders).

Integrating end-of-life care

The health-care system's focus on curative approaches means that health-care professionals are often unfamiliar with palliative care and the skills required to provide it. Furthermore, end-of-life care is most often associated with specialized settings, such as hospice and palliative care units. Consequently, health-care professionals may not associate a palliative approach to care to their particular setting on a busy acute unit or long-term care setting. Yet, the majority of people die in hospital and the number of people dying at home or in long-term care settings is also increasing (Wilson et al., 2009). Only a small proportion of people actually receive end-of-life care in specialized settings and the vast majority of these people die from advanced cancer (Canadian Institute for Health Information, 2007). Although individuals with frailty and non-cancer life-limiting illness could benefit from end-of-life care, clinicians are faced with such challenges as identification of the terminal phase of the disease, changing symptoms and a short period of active dying (Doyle, Hanks, & MacDonald, 1993; Plonk & Arnold, 2005). Improving education on the signs of impending death and integrating the palliative philosophy of care earlier into the disease trajectory, are strategies that could improve care to individuals living with life-limiting illness across health-care settings.

Nursing care at the end of life

Across health-care sectors, nurses – through ongoing assessment, intervention and evaluation – have a unique therapeutic relationship with individuals. Because of this unique position, nurses are able to ensure continuity of care that is responsive to the needs of individuals with life-limiting illness. Integral to the nursing role is advocacy, i.e. initiating and supporting decision-making, providing guidance and information, and collaborating with other health-care professionals (Bryon, Gastmans, & De Casterle, 2008). Due to the frequency of interactions with individuals, nurses are likely to be the first health-care professional to recognize that the person is reaching the last days and hours of life. It is at this pivotal time that nurses can make a significant contribution to the life of an individual nearing death and to his/her family before, during and after the death. Fundamental to end-of-life care is knowledge of issues associated with illness and bereavement, as described in the CHPCA's A *Model to Guide Hospice Palliative Care* (2002) (Figure 2). Complementing this knowledge are nursing competencies required to effectively manage the dynamic and complex situation surrounding end-of-life care (College of Nurses of Ontario, 2010; Canadian Nurses Association, 2008). It is, therefore, not surprising to find that many nurses find caring for individuals during the last days and hours of life challenging and feel ill-prepared to provide end-of life care (Betcher, 2010; Holland & Neimeyer, 2005; Thacker, 2008)

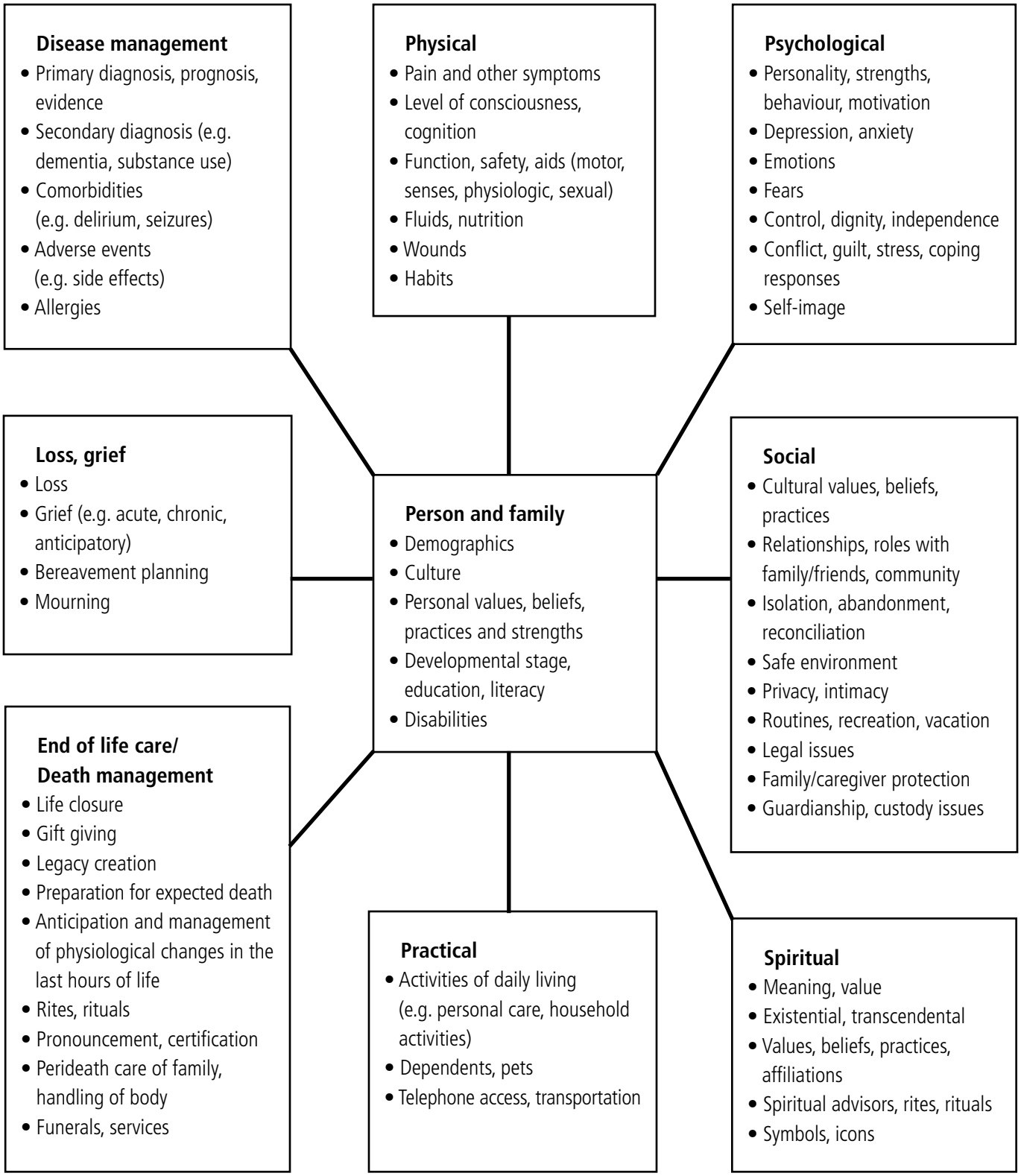

Figure 2. Domain of issues associated with illness and bereavement

Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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Guiding Principles Underlying End-of-life Care During the Last Days and Hours Guideline

The principles and values underlying the development of this guideline are consistent with the palliative care philosophy described above. While we recognize the existence of several models to guide palliative care practice and service provision, the CHPCA's *A Model to Guide Hospice Palliative Care* was the foundation for the development of this guideline as there is national consensus in Canada regarding the use of this model. In addition, this guideline is based on the following beliefs:

- Evidence-based practice is the guiding model for clinical best practice guidelines.
- Evidence-based practice includes the application of the most current research evidence, sound clinical judgment and consideration of individuals' values, preferences and goals of care.
- Evidence-based practice will positively impact the quality of end-of-life care, and individual and system outcomes.
- Each individual has a right to evidence-based quality care during the last days and hours of life.
- Nurses are uniquely positioned, through their frequent therapeutic interactions with individuals and their families, to influence positive outcomes.
- Health systems strategies are required to ensure that each person approaching the end of life has access to care regardless of sector or geographic location.
- Education informed by the best available evidence is necessary for quality end-of-life care.
- Organizational supports and strategies must be in place to translate knowledge into the practice environment.

Purpose

Best practices are emerging guidelines on the approaches and elements of care and treatment that appear to result in successful client outcomes. Given this definition, best practices are recommendations that may evolve, based on ongoing key expert experience, judgment, perspective and continued research (Health Canada, 2008). Best practice guidelines are an accepted method of providing current evidence for nurses to use to guide their practice. These guidelines synthesize the current evidence, and recommend best practices based on this evidence, Appendix B and Appendix C. They offer nurses a reliable source of information upon which to make decisions concerning practice.

The purpose of this best practice guideline is to provide evidence-based recommendations for Registered Nurses and Registered Practical Nurses on best nursing practices for end-of-life care during the last days and hours of life. The guideline does not replace consultation with palliative care specialists, who can support nurses to provide quality end-of-life care. The guideline is intended to be a resource to nurses who may not be experts in this practice area. It is acknowledged that individual competencies vary between nurses and across categories of nursing professionals. The inclusion of recommendations on clinical, education, organization and policy topics makes this guideline applicable to nurses in all domains and settings of practice.

Scope

This guideline focuses on recommendations for adults, aged 18 years and older, who have reached the part of the illness trajectory that includes the last days and hours of life. The clinical questions to be addressed by the guideline are:

1. What knowledge and skills do nurses require to identify and assess individuals and families during the last days and hours of life?
2. What knowledge, skills and tools do nurses require to support individuals and their families in making informed choices during the last hours and days of life?
3. What palliative interventions are needed to address the experiences faced by individuals and their families during the last days and hours of life?
4. What supports are needed to assist nurses in providing high-quality care in the last hours and days of life?

In developing this guideline, we are mindful that the scope of the guideline does not permit an in-depth review of care of individuals dying from particular illnesses and associated issues. Nor does it allow for a comprehensive examination of all elements included in the CHPCA Domains of Issues. Moreover, the focus of this guideline precludes extensive review of issues pertinent to the provision of hospice palliative care across the trajectory of life-limiting illness (Figure 3). Therefore, the development group selected the most common issues encountered by individuals and their families during the last hours and days of life. It should be noted that the RNAO guidelines listed below (www.rnao.org/bestpractices), as well as guidelines developed by other organizations and agencies (Appendix C), can complement this guideline:

- *Assessment and Management of Pain*
- *Establishing Therapeutic Relationships*
- *Client-centered Care*
- *Screening for Delirium, Depression and Dementia*
- *Care Strategies for Individuals with Delirium, Depression and Dementia*
- *Nursing care of Dyspnea: The 6th Vital Sign in Individuals with Chronic Obstructive Pulmonary Disease (COPD)*
- *Supporting and Strengthening Families through Expected and Unexpected Life Events*
- *Bereavement Care*

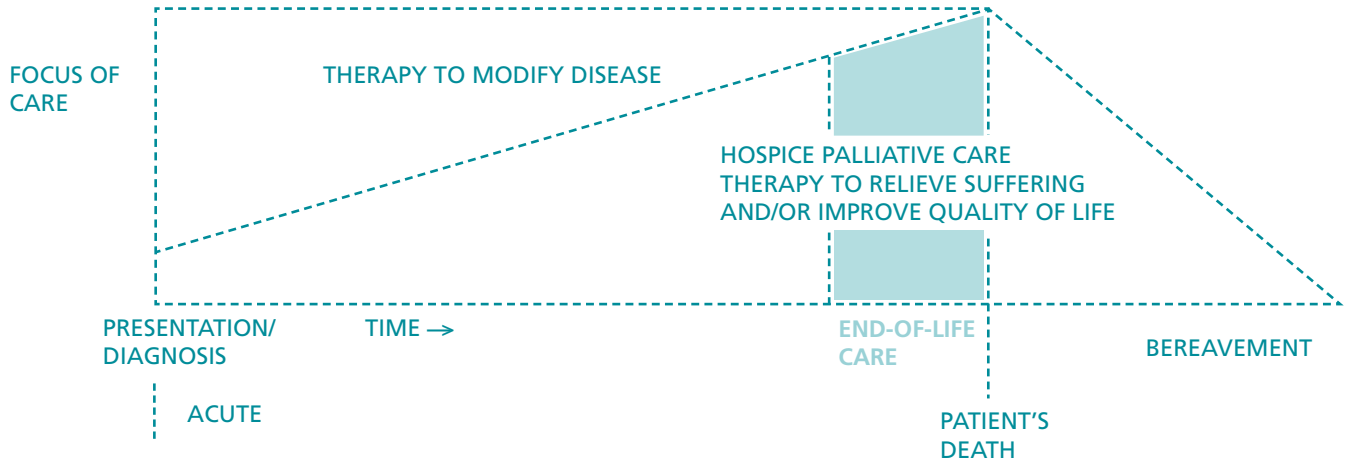

Figure 3. The role of hospice palliative care during illness

Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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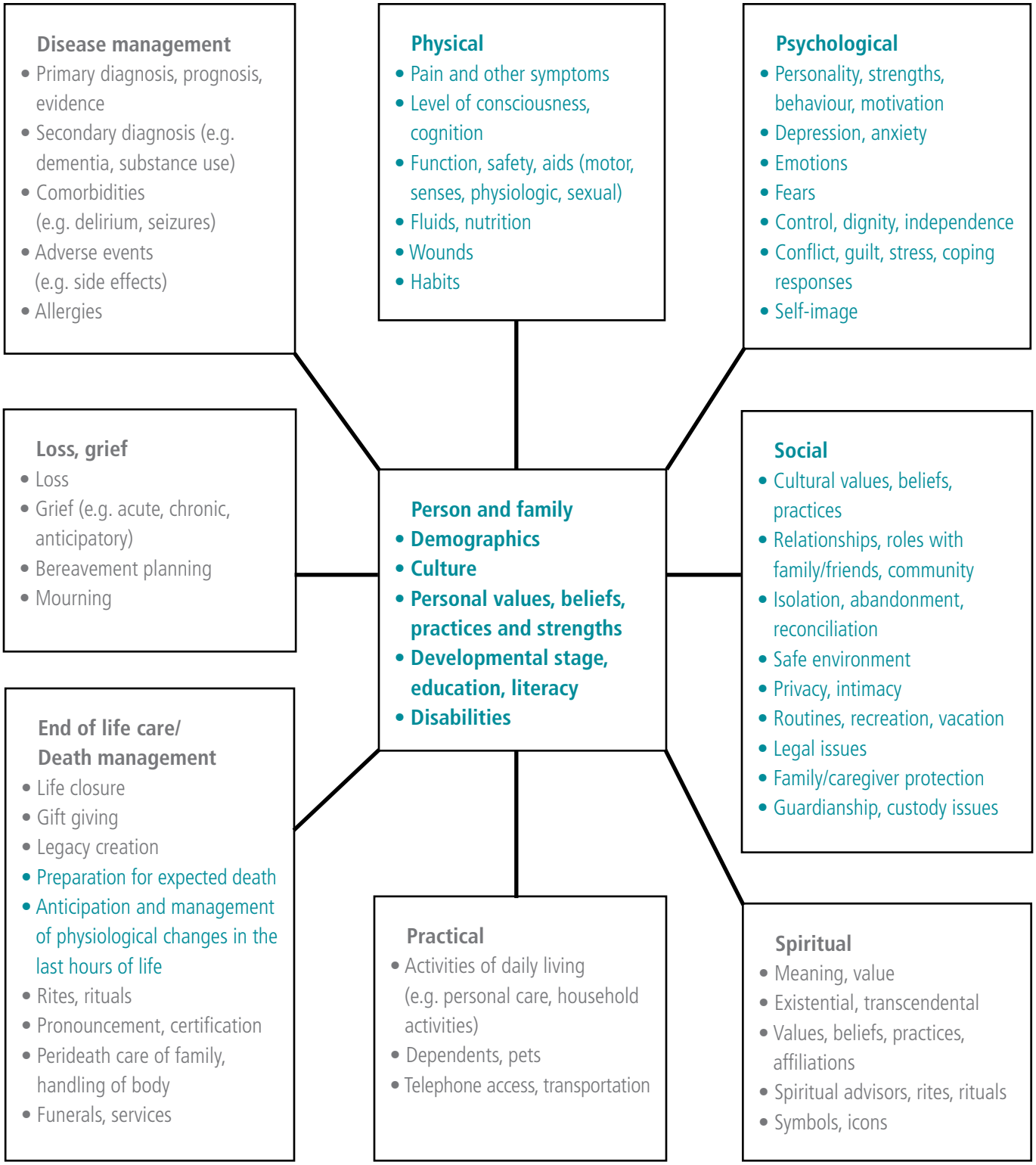
SECTION 1: PRACTICE RECOMMENDATIONS FOR ASSESSMENT AT THE END OF LIFE



Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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Background Context

Throughout the illness trajectory, there are many issues and domains of practice that nurses and health-care teams must consider and address when providing care for individuals at the end of life. While we recognize that consideration for hospice palliative care can begin at any point of the trajectory, this guideline focuses on the last days and hours of life. One aspect is *identifying* individuals who are in the last days and hours of life. This is an important skill, since recognition of impending death and discussion about relevant clinical interventions facilitates identification of end-of-life goals, care preferences, wishes regarding preferred place of death, and planning and implementation of care (Ellershaw, 2003). Failure to identify the signs and symptoms of impending death may lead to futile treatments (e.g. cardiopulmonary resuscitation), as well as conflicts between individuals, their families and the health-care team. Studies have shown that clinicians are often inaccurate in estimating survival times (Lau et al., 2007). Estimates tend to be inaccurate and overly optimistic (Lau et al., 2007). Chow and colleagues (2008) found that clinicians can improve their prediction accuracy with repeated measurement over time and through the application of validated prognostic tools and clinical indicators.

Lynn's (2001) end-of-life trajectories (Figure 4) can assist clinicians in identifying individuals who may benefit from hospice palliative care. The trajectories show three typical patterns of decline for individuals with cancer, chronic illness and frailty:

1. For most cancers there is a short period of obvious decline leading to death.
2. The trajectory for patients with chronic organ failure is characterized by long-term disability with periodic exacerbations and unpredictable timing of death.
3. For those with frailty and dementia, the pattern is characterized by a slow dwindling course to death.

It is important to remember that there may be considerable variation within these patterns and between individuals. In addition, awareness by health professionals of signs of impending death is one way to facilitate recognition and preparation for death.

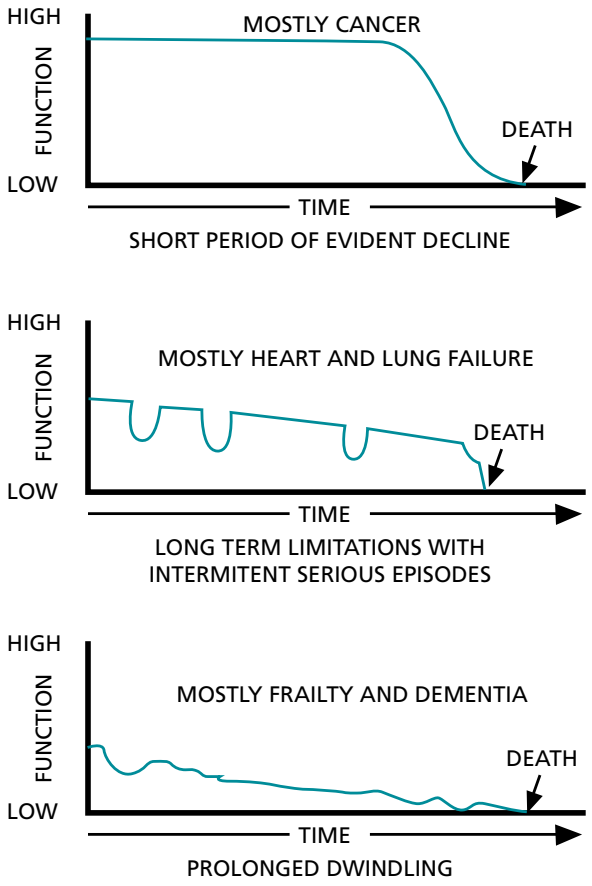

Figure 4. End-of-life trajectories (Lynn, 2001)

Journal of the American Medical Association, 2001, Vol. 285, Issue 7, 925-932
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Preparation for death includes ongoing communication regarding the individual's transition to the dying phase among members of the health-care team, the individual and family. Miscommunication can lead to mixed messages, loss of trust, conflict and poor care management (NCI, 2002; NCCN, 2003). In a study of seriously ill individuals across Canada, Heyland and colleagues (2010) found that family caregivers gained support and felt great relief at being able to talk about their loved one's impending death with nurses. Family caregivers also identified the importance of a team approach, and the need for improved and sensitive communication and information regarding end-of-life care. Heyland and colleagues (2010) also identified several priorities for improving end-of-life care: psychological interventions; spiritual support; enhanced care planning; improved physician/individual relationships; and better communication and decision-making.

Practice Recommendations for Assessment at the End of Life

RECOMMENDATION

1.1 Nurses identify individuals who are in the last days and hours of life.
1.1.1 Use clinical expertise, disease-specific indicators and validated tools to identify these individuals.
1.1.2 Understand the end-of-life trajectories.

Type IIa-IV Evidence

Discussion of Evidence

In several studies, clinical symptoms have been found to be a strong predictor of survival time (Glare, 2004; Harrold, 2005; Lau, 2007; Lau, 2008; Lau, 2009). Other studies have reported a positive association between shortened life span and a range of clinical symptoms such as anorexia, weight loss, dysphagia, dyspnea, congestive heart failure, confusion and delirium (Georges, 2005; Leonard, Agar, Mason, & Lawlor, 2008; Leonard, et al., 2008; Tilden, Tolle, Drach & Perrin, 2004).

Overall, level of functioning appears to be the most important indicator of prognosis (Periera, 2008). Lau (2009) and Harrold (2005) demonstrated the effectiveness of the Palliative Performance Scale, a tool for measuring functional performance and used by caregivers to identify and track care needs as individuals change with disease progression, in predicting the prognosis of individuals with either a cancer or a non-cancer diagnosis, as well as of heterogeneous hospice population of long-term care home residents. Several empirically validated prognostic tools can also aid in recognition of individuals' performance status at the end of life. Some of these prognostic tools (Appendix D) include:

- The Palliative Performance Scale (version 2) (Anderson, Downing, Hill, Casorso, & Lurch, 1996)
- The Palliative Prognostic Index (Chow et al., 2008; Morito, Tsunoda, Inoue, & Chinara, 1999; Stone, Tierman, & Dooley, 2008).
- The Palliative Prognostic Score (Maltoni et al., 1999)

In addition to prognostic tools, clinical indicators are another method of identifying individuals who are approaching the last days and hours of life. Specific indicators of decline are available for congestive heart failure, chronic obstructive pulmonary disease, dementia, renal disease and stroke (Appendix E).

RECOMMENDATION

1.2 Nurses understand common signs and symptoms present during the last days and hours of life.
1.2.1 Common signs of imminent death, may include, but are not limited to:

- progressive weakness;
- bedbound state;
- sleeping much of the time;
- decreased intake of food and fluid;
- darkened and/or decreased urine output;
- difficulty swallowing (dysphagia);
- delirium not related to reversible causes;
- decreased level of consciousness not related to other causes;
- noisy respiration/excessive respiratory tract secretion;
- change in breathing pattern (Cheyne-Stokes respiration, period of apnea); and
- mottling and cooling extremities.

Type IIb – IV Evidence

Discussion of Evidence

Although each individual's death experience is unique, some signs of death are common to most individuals. In the context of a deteriorating or progressive life-limiting illness, and in the absence of reversible factors, Stromgren and colleagues (2006) found that various clinical signs often suggest that an individual is within weeks to days of death. These signs include being bedbound or able to get out of bed only with great difficulty, profound weakness or fatigue, little interest in food and drink, difficulty swallowing and increasing somnolence.

Research investigating the reliability of the above-identified signs is scarce; however, several studies support the presence of these signs. A systematic review of 44 studies conducted by Teunissen, de Graffe, Voest and de Haes (2007) found that fatigue, pain, lack of energy, weakness and appetite loss were the most frequent symptoms, and occurred in more than 50% of individuals during the last one to two weeks of life. Similarly, Elmqvist, Jordohoy, Bjordal, Kassa and Jannert (2009), in a prospective comparative study, demonstrated significant increase in fatigue, dyspnea and appetite loss in individuals with advanced cancer during the last three months of life. Furthermore, a prospective study by Oi-Ling, Man Wah and Kam-Hung (2005) found that individuals rated fatigue, cachexia and loss of appetite as their most distressing symptoms.

Common symptoms of individuals approaching death (Klinkenberg et al. 2004)	
• Fatigue • Shortness of breath • Pain • Confusion	• Depression • Anxiety • Nausea • Vomiting

RECOMMENDATION

1.3 Nurses complete a comprehensive, holistic assessment of individuals and their families based on the Canadian Hospice Palliative Care Association Domains of Care, which include the following:
- disease management;
- physical;
- psychological;
- spiritual;
- social;
- practical;
- end-of-life care/ death management; and
- loss, grief.

1.3.1 Include information from multiple sources to complete an assessment. These may include proxy sources, such as the family and other health-care providers.

1.3.2 Use evidence-informed and validated symptom assessment and screening tools when available and relevant.

1.3.3 Reassess individuals and families on a regular basis to identify outcomes of care and changes in care needs.

1.3.4 Communicate assessments to the interprofessional team.

1.3.5 Document assessments and outcomes.

Type IIb-IV* Evidence

Discussion of Evidence

It is recommended that nurses practice according to the CHPCA Nursing Standards of Practice (www.chpca.net), Canadian Nurses Association competencies in Hospice Palliative Care Nursing, (www.cna-aic.org) and the College of Nurses of Ontario Standards of Practice (www.cno.org) or appropriate jurisdictional practice standards. In addition, nurses are encouraged to apply information from the CHPCA's *A Model to Guide Hospice Palliative Care*, including the Norms of Practice and the Domains of Issues (www.chpca.net). In addition to guidelines developed by other organizations and agencies (Appendix C), several RNAO Best Practice Guidelines are also relevant for care of this population (page 18).

It is imperative that nurses focus on a holistic assessment that extends beyond the physical domain to include other domains outlined by the CHPCA. Wong, Liu, Szeto, Sham and Chan (2004) found that the view of death as a sum of life events, addressing physical, psychological and social needs, is not necessarily appreciated by health-care professionals. Indeed, they found that health-care providers tended to focus more on physical aspects, whereas individuals and families tended to view end of life from a broader perspective that is shaped by a lifetime of experience. Research has shown that individuals and their families identify emotional support, quality of the relationship between physicians and individuals and their families, as well as communication and decision-making as factors that require improvement in end-of-life care delivery (Heyland et al., 2010).

While information gained from the use of validated assessment tools can be helpful, nurses must recognize that the use of these tools may be hindered by cultural and linguistic barriers. The Edmonton Symptom Assessment System (revised version) (ESAS-r) (Appendix F), which is available in multiple languages, is one such validated tool designed to assist in the assessment of 10 common symptoms: pain, tiredness (lack of energy), drowsiness (feeling sleepy), nausea, lack of appetite, shortness of breath, depression (feeling sad), anxiety (feeling nervous), well-being (overall feeling) and constipation. The ESAS-r conveys the individual's description of the severity of the symptom on a scale ranging from 0 to 10 at the time of the assessment. However, the ESAS-r is limited with respect to symptom dimensions; moreover, it measures symptom severity only and not quality, impact, patterns or concurrent symptoms. In addition, since the ESAS-r is designed as a self-reporting tool, many individuals in their last days and hours of life will be unable to complete the assessment. In these circumstances, proxies such as family members and other care providers can be an important source of information for some symptoms. The ESAS-r provides a clinical profile of symptom severity over time; however, it is not a complete assessment in itself, as it covers just one part of a holistic clinical assessment.

CLINICAL TIP

The use of assessment tools suggested in this guideline must be balanced against the burden to the individual.

For individuals who identify pain as an issue, the Brief Pain Inventory (BPI) may be useful. The BPI is a 17-item, multidimensional self-reporting tool that evaluates the intensity, severity, location, chronicity, quality, relief and impact of pain on quality of life (Appendix L).

Despite advances in pain management, it is estimated that up to 2.5 million people around the world die in pain each year (Mehta & Chan, 2008). The tendency to focus on the physical component of pain and exclude other contributing factors may hinder proper pain management. Pain assessment must go beyond the physical triggers and manifestations of pain. Utilizing a comprehensive pain assessment tool will ensure that all parameters are assessed (RNAO, 2007).

When total pain is suspected, health-care professionals must optimize the patient's analgesic regimen and also provide psychosocial and spiritual counseling and support (Pereira, 2008). An understanding of the concept of total pain is a "necessary prerequisite for effective pain management at the end of life" (Mehta & Chan, 2008, p. 28). The total pain model (Figure 5) forms a useful basis for assessment and management of pain in those who are dying. Dame Cicely Saunders, founder of the

modern hospice palliative care movement, coined the term total pain to describe the pain experienced by the dying. She expanded the perception of pain beyond the physical parameter to include psychological, social, emotional and spiritual components. Thus, the assessment of pain in the dying requires a multidimensional assessment, including the individual's biomedical, psychological and psychiatric characteristics, as well as social, family, existential and spiritual influences. Optimal pain relief may be difficult to achieve unless all aspects of total pain are addressed, as psychosocial and spiritual issues may influence severity, intensity and duration of the pain experience. This further highlights the benefits of an interprofessional approach to the care of the dying.

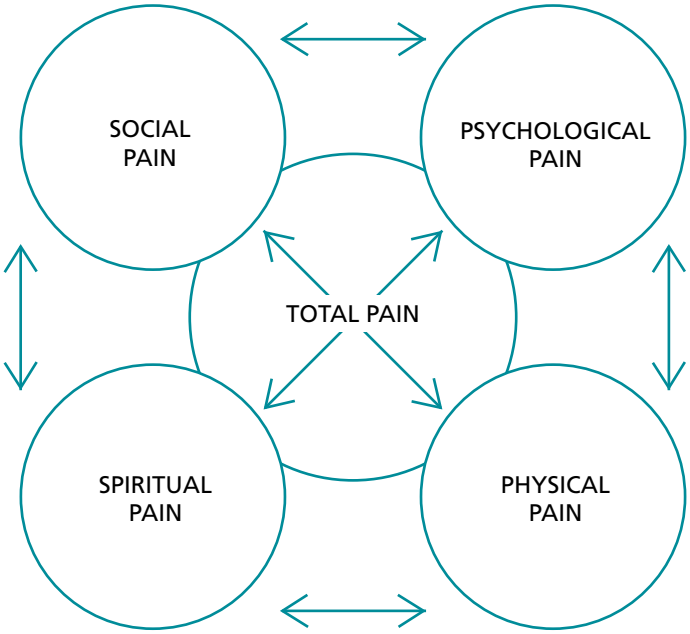

Figure 5. Total pain experience: An interactive model (Mehta & Chan, 2008)

Mehta, A., & Chan, L. (2008). Understanding the concept of "total pain:" A prerequisite for pain control. *Journal of Hospice and Palliative Nursing*, 10, 26–32.

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An awareness of the needs of family members and caregivers is also a critical part of a holistic nursing assessment of the dying individual. Riley and Fenton (2007) found that families and caregivers of dying individuals often experience a wide range of feelings and emotions (e.g. exhaustion, anxiety, depression, sleep disturbance, stress). These feelings and emotions inevitably have negative implications for the health and well-being of families and caregivers.

Despite experiencing negative feelings and emotions, the majority of family caregivers do not access support for themselves. Reasons given include a lack of awareness of services, the need to be seen to be coping, anxiety about leaving their family member or partner alone and fear of upsetting their family member or partner (Riley & Fenton, 2007). Consequently, many families and caregivers experience feelings of isolation, depression and engagement in behaviours that compromise their health.

Several validated tools are available to facilitate assessment of families and caregivers (Table 1).

Table 1. Tools for assessment of families and caregivers

Category	Areas to Assess	Possible Questions	Assessment tools
Context	Relationship to care recipient Physical environment (home, facility) Household status (number in home, etc.) Financial status Quality of family relationships Duration of caregiving Employment status (work/home/volunteer)	What is the caregiver's relationship to the care recipient? How long has he/she been in the caregiving role? Does the care recipient live in the same household as the caregiver? Is the caregiver married? What is the caregiver's household income? Does he/she have children? How many people live in the caregiver's household? Are other family members or friends involved in the care? Is the caregiver currently employed? Full-time or part-time? How would the caregiver rate his/her quality of family relationships?	
Caregiver values and preferences	Caregiver/care recipient willingness to assume/accept care Perceived obligation to provide care Culturally based norms Preferences for scheduling and delivery of care and services	Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care? Does the caregiver feel he/she is obligated to provide care? What types of care arrangements are considered culturally acceptable for this family? What are the caregiver's (and care recipient's) preferences for scheduling and delivery of care and services?	Family Members' Care Expectations (Kristjanson, Leis, Koop, Carriere, & Mueller, 1997) Family Inventory of Needs (Kristjanson, Atwood, & Degner, 1995)

Category	Areas to Assess	Possible Questions	Assessment tools
Well-being of the caregiver	Self-rated health: • Health conditions and symptoms • Depression or other emotional distress (e.g. anxiety) • Life satisfaction/quality of life	How does the caregiver rate his/her own health? Does the caregiver rate his/her health better, about the same, or worse than it was 6 months ago? Does the caregiver have any health conditions or symptoms? How often in the past 6 months has the caregiver had a medical exam or received treatment for physical health problems from a health-care practitioner? **Depression Scale** How often does the caregiver feel anxious or angry when he/she is around the care recipient? How often does the caregiver get a full night's sleep? How does the caregiver rate his/her life satisfaction and/or quality of life?	Caregiver Reaction Assessment (Given et al., 1992) Hospital Anxiety and Depression Scale (Zigmond & Snaith,1983) Caregiver Quality of Life Index (McMillan & Mahon, 1994) Caregiving at Life's End Questionnaire (Salmon, Kwak, Acquaviva, Egan, & Brandt, 2005) Quality of Life in Life Threatening Illness – Family Carer Version (Cohen et al., 2006)
Consequences of caregiving	Perceived challenges	Does the caregiver have a social support network or is he/she isolated? Does the caregiver suffer any work-related difficulties due to the caregiving role? Does the caregiver suffer from any emotional and/or physical health problems as a result of caregiving? How much does the caregiver's health stand in the way of doing things he/she wants to do? What has been the financial strain, if any, on the caregiver due to his/her caregiving role? How much disagreement has the caregiver experienced with other family members over particular care issues?	Caregiver's Burden Scale in End-of-life Care (Elmstahl, Malmberg, & Annersted, 1996) The Hospice Caregiver Assessment (Etten & Kosberg, 1989) Caregiver Strain Index (Robinson, 1983) The Caregiver Reaction Assessment (Given et al., 1992)

Category	Areas to Assess	Possible Questions	Assessment tools
	Perceived benefits	Does the caregiver feel satisfaction in helping a family member? Does the caregiver feel he/she has developed new skills and knowledge as a result of caregiving? Has there been an improvement in family relationships (general closeness, communication, similarity of views, and degree of getting along) as a result of the caregiving situation?	Caregiver Mutuality Instrument (Archbold, Stewart, Greenlick & Harvath, 1990) Caregiver Reaction Assessment (Given et al., 1992)
Caregiver skills/ abilities/ knowledge to provide care	Caregiving confidence and competencies Appropriate knowledge of medical care tasks (wound care, etc.)	How knowledgeable does the caregiver feel about the care recipient's condition? What are the skills and abilities needed to provide care for the care recipient? How would the caregiver rate his/her confidence and competence in these areas? Does the caregiver have the appropriate knowledge of medical care tasks (wound care, ability to administer medications correctly, etc.) and transfer techniques (moving from bed to chair, etc.)?	Caregiver Competence Scale (Pearlin, Mullan, Semple, & Skuff, 1990) Preparedness for Caregiving Scale (Archbold & Stewart, 1996) Caregiving Mastery (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) Caregiver Self-Efficacy (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999)
Caregiver resources	Helping network and perceived social support Existing or potential strengths (e.g. what is presently going well) Coping strategies Financial resources (healthcare and service benefits, entitlements such as Veteran's Affairs, insurance benefits) Community resources and services (caregiver support programs, religious organizations, volunteer agencies)	Can the caregiver rely on his/her social support network for help (i.e. respite)? What are the caregiver's coping strategies? Are these healthy/ constructive? Has the caregiver accessed all financial benefits and entitlements he/she or care recipient is eligible for (e.g. Veteran's Affairs)? What other community resources/services is the caregiver utilizing or aware of (e.g. caregiver support groups, religious organizations)?	Social Support Questionnaire Brief Form (Sarason, Sarason, Shearin, & Pierce, 1987) Care Evaluation Scale (Morita et al., 2004) FAMCARE Scale (Kristjanson, 1993)

Adapted from: Family Caregiver Alliance. (2006). *Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers.* San Francisco: Family Caregiver Alliance.

RECOMMENDATION

1.4 Nurses:
- reflect on and are aware of their own attitudes and feelings about death;
- assess individuals' preferences for information;
- understand and apply the basic principles of communication in end-of-life care;
- communicate assessment findings to individuals (if possible and desired) and the family on an ongoing basis;
- educate the family about the signs and symptoms of the last days and hours of life
- with attention to their: faith and spiritual practices; age-specific needs,
- developmental needs; cultural needs; and
- evaluate the family's comprehension of what is occurring during this phase.

Type III-IV Evidence

Discussion of Evidence

Defner and Bell (2005) found that nurses' anxiety levels in caring for dying individuals had an inverse relationship to their comfort level when communicating with individuals and families regarding death. Therefore, it is important that nurses be aware of their own attitudes toward death and dying so that they are able to support individuals. A validated tool that can help nurses identify their own attitudes toward death and dying is the Frommelt Attitude Toward Care of the Dying Scale (Appendix G). Heyland and colleagues (2010) noted that emotional support of both the individual and their family was a high priority for improvement in end-of-life care. Similarly, Goodridge, Bond, Cameron & McKean (2005) found that caring behaviours of staff are central to the dying experience and encompass a wide range of activities. Professional activities, such as assessment and coordination of care, were not readily evident to either families or unregulated health-care providers, except in their absence, but were recognized by nurses to be crucial components of end-of- life care. High quality end-of-life care was deemed to be important by families, nurses and unregulated health-care providers. Ensuring that the individual was as physically comfortable as possible was the overriding goal of all staff.

Goodridge and colleagues (2005) reported that families require information about the significance and probable sequence of physical signs of impending death, as well as relevant interventions. Evidence is inconclusive as to whether information should be provided as anticipatory guidance or on a need-to-know basis (Moody, 2004). Written information (e.g. pamphlet or booklets) can be provided, but should be regarded as supplementary to verbal communication with health-care professionals. Nonetheless, it is critical that information is provided to individuals. Indeed, a systematic review of studies by Clayton (2007) regarding the concept of hope during discussions about prognostic and end-of-life issues with terminally ill individuals and their families, found that hiding or distorting the truth did not engender hope and rendered the situation more frightening.

CLINICAL TIP

Family conferences have been shown to decrease anxiety, support decision-making and goal setting (Weissman, 2000). Appendix H outlines tips for conducting a family conference.

PRACTICE BOX: CLINICAL HIGHLIGHTS

- Education of families about the process of dying and what to expect after a death is a key element of nursing interventions.
- Information about the significance and probable sequence of the physical signs of dying and the interventions that may be used to address the symptoms must form the basis for education.
- Discussion of families' expectations regarding who will be present at the time of death is helpful.
- While it is not usually possible for a staff member to be constantly in attendance with a dying individual, families require reassurance that staff will check on the individual regularly.
- Individuals and caregivers prefer honest and accurate information that is provided with empathy and understanding.

Dying individuals experience fear of pain, indignity, abandonment and the unknown (Chochinov, 2002). Involving individuals and their family members in discussions regarding these fears may strengthen relationships within the family and reduce the isolation experienced by the dying person (Herrmann & Zulisn, 2008).

Recognition of the importance of emotional support and nurturance at the end of life implies that nurses must be equipped with sufficient human resources and knowledge to adequately address this need. Other guidelines reviewed by the development panel that met the AGREE criteria (an internationally recognized tool to assess the quality of clinical practice guidelines, Appendix B), indicate that the individual's transition to the dying phase should be consistently communicated by all members of the health-care team. Mixed messages should be avoided as they can lead to loss of trust, miscommunication, conflict and poor care management (NCI, 2002; NCCN, 2003). As well, nurses should be aware that the focus of hope at this stage often shifts from cure and prolongation of life to quality of living and dying (Singer et. al., 1999; Stajduhar et al., 2008).

SPIKES: A SIX-STEP STRATEGY FOR DELIVERING BAD NEWS (BAILE ET AL., 2000, P. 305-307)

1. S – Set up the Interview

a. Arrange for a private location to meet.
b. Involve significant others.
c. Sit down and try not to have barriers between you and the patient.
d. Make connection through eye contact and touch.
e. Manage time constraints and interruptions.

2. P – Assess the individual's perception

a. Use open-ended question, i.e. "What have you been told about …" or "What is your understanding of …"
b. Correct misinformation and tailor bad news to the individual's understanding.

3. I – Obtain the individual's invitation

a. A person's desire for information may lessen his/her anxiety associated with the bad news.
b. If information is not desired, offer to answer any questions.

4. K – Give knowledge and information to the individual

a. Provide warning that bad news is coming, to lessen the shock that follows the disclosure of bad news.
b. Assess the level of comprehension and vocabulary of the individual.
c. Use non-technical terms.
d. Avoid excessive bluntness.
e. Give information in small chunks and check periodically regarding patient/caregiver understanding.

5. E – Address the individual's emotions with empathic responses

a. Observe for any emotion experienced by the individual.

b. Identify emotions experienced by the individual.

c. Identify the reason for the emotion.

d. Connect the emotion by making a connecting statement, such as "I am sorry about _____. I know this is not what you want to hear. I wish the news were better."

6. S – Strategy and summary

a. Establish clear plan for the future, to lessen feeling of anxiety and uncertainty.

Limitations of the Evidence and Future Directions

There is a paucity of data to support various interventions during the last days and hours of life, largely due to the difficulty in recruiting individuals who are dying into research studies. In addition, few tools regarding care of people who are dying have been validated in the non-cancer population. There is also a lack of evidence regarding the knowledge and skills required to provide care for these individuals. Further research is clearly required in these areas. Thus, much of the evidence supporting these recommendations is based upon expert clinical consensus, consensus guidelines and standards of practice.

SECTION 2: PRACTICE RECOMMENDATIONS FOR DECISION SUPPORT AT THE END OF LIFE

Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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Background Context

Individuals face numerous social, health, lifestyle and practical decisions when living with end-stage, life-limiting illness (McPherson, Wilson, & Murray, 2007; Murray, 2007; Murray, Fiset, Young, & Kryworchuko, 2007; Murray, Pollack, White, & Lo, 2007). These include major decisions regarding withdrawal of treatment, preferred place of care, hydration and nutrition, as well as daily care decisions such as personal hygiene and who will be involved in care activities. Findings from a study that examined the context of end-of-life decision-making indicated that values, beliefs and experiences greatly shape individuals' decision-making (Gauthier & Swigart, 2003). The unclear nature of outcomes and knowledge of how each person will respond to interventions can render decision-making uncertain and difficult, and can lead to decisional conflict. Many individuals feel uncertain about the best course of action for them (O'Connor, 2005).

Decisional conflict can be exacerbated by the following: not knowing what options are available; having insufficient information about options and probabilities of adverse consequences; being unclear about their personal values regarding the available options; and not feeling supported in decision-making (O'Connor, Jacobsen, & Stacey, 2002). Nurses can help individuals meet their decision-making needs by providing decision support through counselling and decision coaching, and by using patient decision aids (Stacey et al., 2008). Decision support from the health-care team can be effective in helping individuals participate in decision-making (Coulter & Ellins, 2007).

To reach quality decisions, individuals must be informed about their options, and understand the potential risks and benefits associated with those options. As well, based on their personal beliefs and values, they need to be allowed to express clearly what they consider to be the most important potential outcomes to avoid or achieve associated with the options presented. Finally, patients need to be supported to express their preferences.

Shared Decision-Making

Individuals have a right to know their options and to have their preferences considered. Supporting individuals who are nearing the end of life requires interprofessional collaboration and problem-solving. Shared decision-making can help individuals participate in the decision-making process in ways they prefer and can help to meet their decision-making needs.

Shared decision-making occurs when health-care providers and individuals work together to make health-care choices and develop a plan of care. Findings from several studies indicate that nurses play a role either directly or indirectly in end-of-life decision-making (e.g. advocating for individuals' rights to participate in decision-making, or helping prepare individuals to participate in decision-making) (Baggs & Schmitt, 2000; Frank, 2009; Murray, O'Conner, Fiset, & Viola, 2003; Oliverio & Fraulo, 1998; Thompson, McClement, & Daenick, 2006).

SHARED DECISION-MAKING

In shared decision-making, practitioners communicate known scientific evidence and patients bring information about what is most important and practical to their situation (Charles, Gafni, & Whelan, 1997). Decision support attempts to reconcile these two points of view so that quality decisions, informed by the best available evidence and patient values, emerge.

Practice Recommendations for Decision Support at the End of Life

RECOMMENDATION

2.1 Nurses recognize and respond to factors that influence individuals' and their families' involvement in decision-making.

Type Ib, IV, IV* Evidence

Discussion of Evidence

Evidence confirms that nurses are able to recognize individuals' cues regarding their desire to engage in discussions about end-of-life care (McMillen, 2008). For example, nurses working in intensive care units identified providing input into decisions about directions of care as an important role that was recognized by physicians (McMillen, 2008).

Supporting individuals in decision-making requires an understanding of the range of responses that patients experience. Individuals vary in their tolerance of discomfort, will to live and uncertainty. These factors can also vary within the same individual over time, and across different situations and circumstances (Murray, 2003). Moreover, the meaning of suffering is influenced by cultural, spiritual and religious traditions (Loomis, 2009).

To provide timely decision support, nurses must recognize the common decisions faced by individuals and their families, and identify areas of uncertainty (Murray, 2004; Murray, 2009; Voltz, 1998).

Advance Care Planning and Decision-making

Advance care planning is a process whereby an individual makes decisions about his or her future health care, either independently or in consultation with family and care providers (Siner, Roberston, & Roy, 1996). Elements of advance care planning include:

- clarifying the patient's understanding of their illness;
- elucidating the situation and treatment options;
- understanding the patient's values, priorities and goals of care;
- identifying and documenting the patient's wishes; and
- nominating a substitute decision-maker for a time when the patient may not be able to make decisions independently (Romer & Hammes, 2004).

A randomized controlled trial comparing usual care or usual care plus facilitated advance care planning with 309 competent medical inpatients aged 80 years or older was conducted recently in Australia. The results confirmed that advance care planning improves end-of-life care and patient and family satisfaction, and reduces stress, anxiety and depression in surviving relatives (Detering, Hancock, Reade, & Silvester, 2010).

ADVANCE CARE PLANNING DISCUSSIONS

Ideally, advance care planning discussions should take place before a health crisis occurs and/or at diagnosis, and be revisited regularly throughout care and treatment (Health Canada, 2008).

Nurses and the health-care team should review decisions made previously, as well as advance care plans, as goals and subsequent plans of care can change based on the individual's circumstances, clinical condition and availability of resources (Murray, Wilson, Stacey, Kryworuchko, & O'Conner, 2009). Nurses must remember that advance care plans do not replace informed consent, if individuals have expressed their wishes regarding future health care, then health-care providers must still obtain consent or refusal to consent prior to initiating a treatment plan (Wahl, 2003).

Factors that Influence Individuals' and Families' Involvement in Decision-making at End of Life

Factors that may influence an individual's involvement in decision-making are mapped to domains of issues, as described in the CHPCA's square of care in A Model to Guide Hospice Palliative Care (Appendix I).

Square of care category	Factors influencing decision-making	Sources
Physical	• Physiological distress	Gauthier (2005)
Psychological	• Not wanting to burden other family members.	McPherson (2007); Hanna-Mari & Maria-Liisa (2006)
	• Fear of causing added anxiety by discussing end-of-life decision-making.	Murray (2003)
	• Discriminating between preferred and best choice.	Loomis (2009)
	• Unresolved issues, incomplete dreams, fear of losing control and fear of the unknown can deeply influence treatment choices.	Marion (2007)
	• Lack of communication and support.	Handy (2008); Murray (2003)
	• Finding decision-making very overwhelming.	Thelen (2005); GAC (2008)
Social	• Lack of an individual approach to end of life and use of a "one size fits all" approach.	Mazanec & Tyler (2003)
	• Lack of capacity to respond to diverse cultural needs.	Mazenac (2003)
	• Miscalculation of consequences of end-of-life decisions on patient's quality of life and functional state.	Hanna-Mari & Marja-Liisa (2006); Cox et al. (2006);
	• Culture, ethnicity and lack of knowledge of patient's cultural background, beliefs and traditions.	Meeker (2009); Mazenac (2003); Meeker & Jezewski (2005)
	• Lack of clarity in language used and contradictory messages delivered by different clinicians.	
Spiritual	• Spirituality and hope influences decision-making.	Gauthier (2005)
Practical	• Lack of knowledge about patient's/family's preferences.	Loomis (2009)
	• Lack of concordance between patient's preferred choice and substitute decision-maker's perception of that choice; availability of services and supports.	Meeker (2009)
	• Difficulty in articulating preferences.	Moorman (2008)
	• Difficulty accessing the providers to secure information.	Meeker & Jezewski (2005)

Square of care category	Factors influencing decision-making	Sources
End-of-life/Death management	• Type of decision.	Hansen, Archbold & Stewart (2004)
	• Lack of knowledge of signs of imminent death; perceptions of 'good death' or 'bad death.'	Thelen (2005); GAC (2008)
	• Unrealistic expectations that advance care plans occur in a single meeting; belief that another health-care provider has initiated discussions about advance care planning.	Meeker (2009)
	• Health-care providers downplay caregiver's concerns.	Handy et al. (2008)
	• Health-care providers can powerfully facilitate or obstruct surrogate decision-making.	Hassen et al. (2005)
	• Health-care provider belief that it is not appropriate to begin advance care planning on an outpatient basis.	Meeker & Jezewski (2005)
	• Lack of honesty and direction of health-care provider.	Warm (2005)
	• Limited opportunity or time to listen to family members' concerns and respond directly to these concerns.	ICIS (2008); Meeker & Jezewski (2005); Curtis et al. (2005)
	• Lack of communication between health-care providers can cause confusion regarding treatments and interventions.	Kass-Barteimes (2004)

Factors that can Help Individuals and Families Engage in Decision-making

- An individual's level of interest and ability to participate in decision-making (Davison & Torgunrud, 2007).
- Perception of personal level of control and power, as well as perceived differences in power and authority (Davison & Torgunrud, 2007).
- Perceived benefits of participation (Davison & Torgunrud, 2007).
- Resources to participate (Davison & Torgunrud, 2007).
- Identification of the person with whom the individual wishes to engage in decision-making discussions (Davison & Torgunrud, 2007).
- Quality, frequency and availability of communication with care providers (Meeker & Jezewski, 2009).
- Recognizing the role of the physician and their involvement in facilitating completion of advance care plans (Barrett, 2005).

How Providers can Help Individuals Engage in Decision-making

Examples of strategies nurses can use to help patients to engage in decision-making are provided in Appendix J. Specific nursing actions include:

- Assess individual's and family members' perceptions about their situation and options.
- Offer clear, thorough information.

- Assist with advance care planning.
- Provide timely information in a manner that the individual can comprehend, by using concrete examples and lay language.
- Acknowledge and address emotions, and provide grief support.
- Help individuals to clarify their values.
- Provide consistent care providers.
- Listen and respond to family members' comments.
- Assess for conflict within the family.
- Act as an arbitrator between family members and provide time for discussion.
- Help family members to achieve consensus.
- Validate the importance of hope within the context of uncertainty.
- Facilitate ongoing communication between individuals and family members.
- Assess the individual's and family members' competence for decision-making.
- Embed opportunities for shared decision-making throughout the end-of-life trajectory.
- Refer to established ethical guidelines as needed.

PRACTICE BOX: NURSES' ROLES IN END-OF-LIFE DECISION-MAKING

1. **Nurses assist an individual in participating in decision-making, to the extent that the individual desires.**
   People with life-limiting illness make health and personal care decisions in response to daily challenges and uncertainty. Nurses may anticipate decisions that individuals will likely face based on their clinical knowledge and by recognizing when an individual is experiencing decisional conflict.

2. **Nurses recognize common decisions individuals and families may face in the last days and hours of life. Common decisions may include:**
   - Should I begin/continue/discontinue a particular treatment?
   - Should I make plans to receive care in a place other than my home?
   - Should I discuss my wishes for care and treatment planning with my family?
   - Should I appoint someone to be my substitute decision-maker?

3. **Nurses determine and respond to individuals' decision-making needs.**
   To provide effective decision support, nurses must recognize individuals facing decisional conflict. O'Connor (2008) suggested the following as typical signs of decisional conflict:
   - being unsure about what to do;
   - concern about negative outcomes;
   - distress or upset;
   - preoccupation with the decision;
   - wavering/vacillation;
   - delay making the decision;
   - questioning what is important; and
   - physical signs of stress.

   In addition to decisional conflict recognition, nurses must also identify the source of uncertainty. Factors that contribute to a individual's decisional conflict include: uncertainty about prognosis; having more than one option; fear of regret that an option not chosen cannot be modified.

However, several factors can be addressed, including: knowledge about options and the potential consequences associated with each option; being clear about which consequences are most important to achieve or avoid; and feeling pressured or unsupported in the decision-making process. Nurses can intervene to address individual's unmet decision-making needs by (Stacey et al., 2008):

- providing information about options, and the benefits and harms associated with each option;
- assessing an individual's understanding of information about options, and the benefits and harms associated with each option;
- assisting individuals to clarify what factors associated with each option are important to achieve or avoid;
- helping individuals build skills in deliberation and communication;
- assessing support needs;
- monitoring and facilitating progress in decision-making; and
- screening for implementation needs.

RECOMMENDATION

2.2 Nurses support individuals and families to make informed decisions that are consistent with their beliefs, values and preferences in the last days and hours of life.

Type Ia-IV* Evidence

Discussion of Evidence

Supporting patient decision-making

Given their ongoing therapeutic encounters with individuals and families, nurses play a significant role in supporting them in decision-making processes related to identifying and carrying out goals of care in the last days and hours of life (Murray, Oddi, & Cassidy, 1998). Individuals who are informed about their prognosis and their options (e.g. hospice palliative care) are more likely to take an active role in their own end-of-life care (Huang, 2008).

Tools and processes to support patients in decision-making

Strong evidence from randomized trials confirms that nurses can build skills in decision support and are able to provide better quality of individual decision support following a targeted education intervention (Murray, O'Connor, Stacey, & Wilson, 2008; Stacey et al., 2006). In a non-randomized trial undertaken to evaluate an intervention designed to help nurses' support patient decision-making, approximately one-half of participants felt they were unable to uphold individuals' wishes and experienced job dissatisfaction due to perceived inappropriateness of level of care delivered prior to the intervention. Following the intervention, however, nurses were better able to effectively advocate for individuals' involvement in decision-making and perceived that when patients were empowered to exercise self-determination, their care was more satisfying and consistent with individual preferences (Marion, 2007).

A systematic review of 86 randomized controlled trials confirmed that patient decision aids can be effective in helping prepare patients to participate in decision-making (O'Connor, 2006). Specifically, in a randomized controlled trial of palliative care providers, which combined a patient decision aid for place of end-of -life care and a decision coaching education intervention, participants who received the intervention were significantly better able to provide quality decision support than those who did not receive the intervention (Murray et al., 2009).

PRACTICE BOX: NURSES' ROLES IN END-OF-LIFE DECISION-MAKING

1. **Nurses use valid and reliable tools to support patients make end-of-life decisions.**
   Generic, valid, and reliable tools are available and can be used in the context of end-of-life care. For instance, the Ottawa Hospital Research Institute's Patient Decision Aids webpage (www.decisionaid.ohri.ca), contains a number of practical tools and resources to help patients and their families who are facing end-of-life-decisions.

   Other tools to assist individuals and families in communicating their choices are available at the Ontario Seniors' Secretariat website (http://www.seniors.gov.on.ca) or the British Columbia Fraser Health Authority website (www.fraserhealth.ca).

2. **Nurses are aware of how their verbal and non-verbal interactions with individuals and families, as well as other care providers, can influence people's participation in decision-making.**
   Decision coaching provides a way to help support individuals through the decision-making process (Stacey et al., 2008). In decision coaching, providers who are supportive but non-directive, guide individuals through the decision-making process. The intent is to help individuals to develop their skills and confidence in deliberating and making choices, and the goal is to prepare individuals to discuss decisions with their practitioners (O'Connor, Stacey & Lagare, 2008; Stacey et. al, 2008).

   Findings from several randomized controlled trials (not specific to end-of-life care) have shown that decision coaching improves the quality of individual's decision-making (Bekker, Hewison, & Thornton, 2004; Deschamps, Taylor, Neubauer, Whiting & Green, 2004; Green et. al., 2001; Green et. al, 2004; Hunter et al., 2005; Kennedy et. al., 2002; Lalonde, O'Connor, Duguay, Brassard, Drake, & Grove, 2006; Lerman, et. al., 1997; Miller et. al., 2005; Myers et al., 2005; Rothert et al., 1997). Specifically, decision coaching helps to engage individuals in the decision-making process, facilitates their involvement, improves their knowledge about available options and improves their satisfaction with the decision-making process. In principle, these findings could be transferable to decision coaching in the context of end-of-life care.

Table 2 summarizes findings from studies showing the influence of nurses on conversations about care planning. It also illustrates evidence associated with individuals' participation in decision-making and actions that nurses can undertake.

Table 2. Nurses influence on care planning and decision-making discussions

Nurse/patient relationship	Sharing of power and control	Communication and assessment
Promote discussion if families are struggling with conflict (Hsieh, Shannon & Curtis, 2006).	Emphasize the need to consider what information was essential for patients and relatives, to use concrete examples and lay language, and provide time for decision-making (Hanna-Mari & Marja-Liisa, 2006).	Offer emotional and existential support through discussion, listening, being present and attending to patients and relatives (Hanna-Mari & Marja-Liisa, 2006).
Raise issues related to end-of-life care early in the course of a life-threatening illness (Thelen, 2005).	Provide resources regarding how to access reliable information (National Advisory Committee: *A Guide to End-of-life Care for Seniors)*.	Evaluate patients' and their relatives' competence for decision-making and support them in accepting the prognosis (Hanna-Mari & Marja-Liisa, 2006).
Approach the topic sensitively (National Advisory Committee: *A Guide to End-of-life Care for Seniors*).	Be aware of the authority that providers have in influencing decisions by critically analyzing/reflecting upon the extent to which they have control over a patient's situation (Hilden & Honlasalo, 2006).	Clarify patients' and their relatives' views (Hanna-Mari & Marja-Liisa, 2006).
Be available to listen to concerns and provide uninterrupted time (National Advisory Committee: A Guide to *End-of-life Care for Seniors*).	Reframe decisions regarding withholding or sustaining treatment as allowing the disease to take its course rather than "not continuing treatments that merely prolong suffering." (Lyness, 2004)	Patients and their families need to understand their overall medical condition to plan effectively. They also need to know how their illness and various treatment options will affect them within the context of their daily lives (Davison & Torgunrud, 2007).
Recognize that each person has a unique tolerance for discomfort and a unique drive to live (Loomis, 2009).	Recognized that people may choose to endure physical or emotional distress as part of their spiritual journey (Loomis, 2009).	Facilitate frank assessment of the likelihood of whether withholding or sustaining treatment will be beneficial (Lyness, 2004).

Limitations of the Evidence and Future Directions

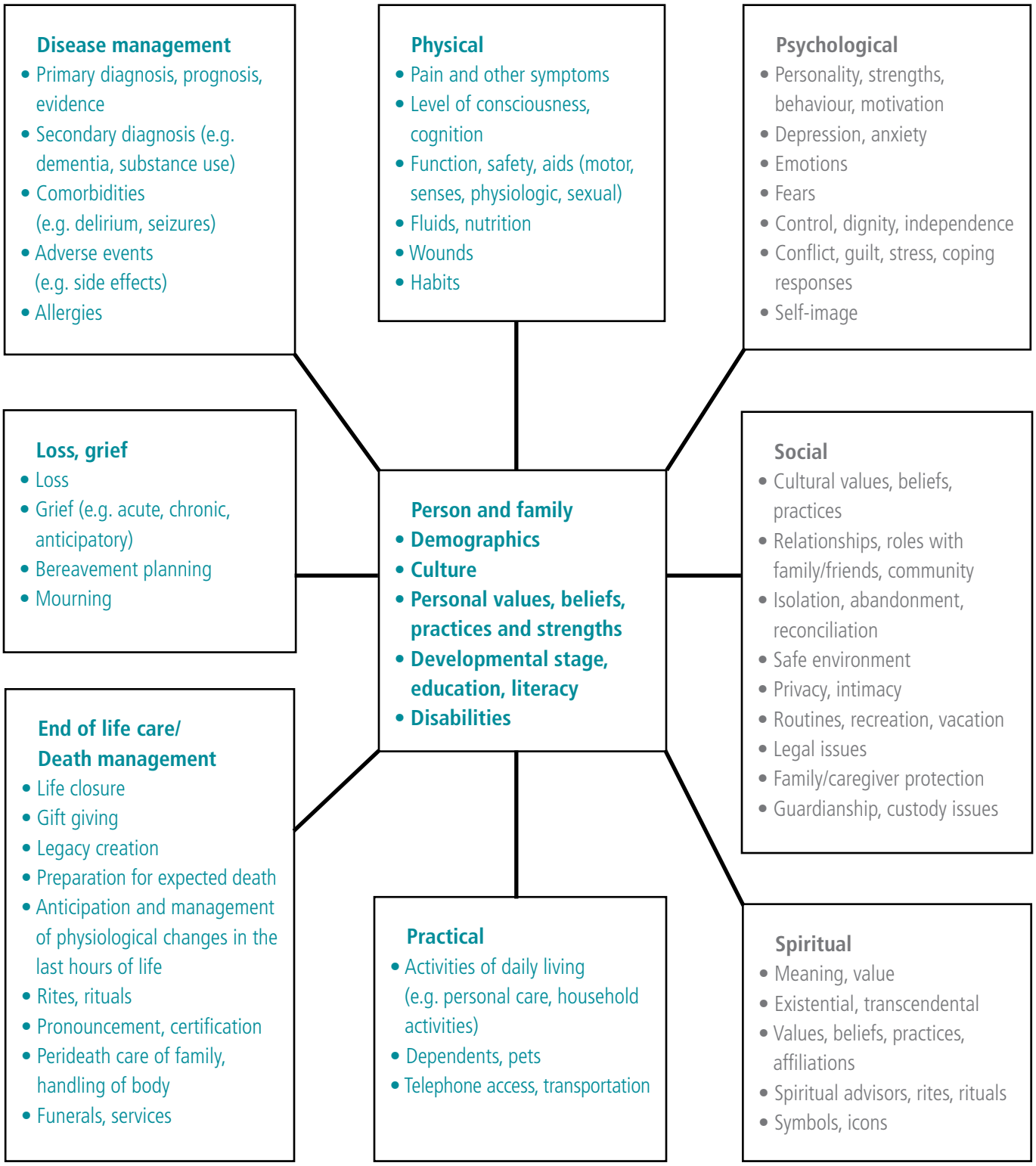
Much of the evidence for end-of-life care interventions, particularly evidence related to decision support, has not specifically targeted care in the last days and hours of life. Thus, our understanding of how to provide support within clinical pathways is imperfect. Clearly, there is a pressing need to develop and implement applied research studies and quality improvement initiatives that focus on the last hours and days of life.

At the very end of life, changes in cognition and awareness fluctuate and occur often. How to best address this changing dynamic has not been well explored. Establishing clear directions about when and how to engage substitute decision-makers while respecting individuals' autonomy is often difficult and is an area requiring further investigation.

While strong evidence confirms that building skills in the area of decision support helps nurses to provide quality decision support, there has been limited integration of education programs to assist nurses in attaining these skills. As well, embedding decision support interventions into moments of care and care planning activities has generally not occurred in clinical practice settings. This too is an area requiring urgent attention.

While calls for interprofessional collaboration have been made, discussions surrounding decision-making are often deferred to particular disciplines such as medicine and social work. As collaborative practice becomes more fully integrated in the clinical arena, health-care teams must discuss who would be most appropriate to take a lead role in care planning at various times in the trajectory of the illness. How to best facilitate knowledge transfer and sharing of outcomes of decision-making discussions among team members and other stakeholders also requires clarification. As well, clear links between how an individual's participation in decision-making affects individual and system outcomes have not been established due to methodological constraints of previous studies and lack of defined indicators. An inventory of indicators with attendant definitions would assist providers and researchers in addressing this gap and could help synthesize evidence in meaningful ways.

SECTION 3: PRACTICE RECOMMENDATIONS FOR CARE AND MANAGEMENT AT THE END OF LIFE



Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002

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Background Context

Individuals and their families face many complex issues at the end-of-life. As highlighted in Sections 1 and 2, nurses play an essential role in assessing and supporting individuals during this period (Bryon et al., 2008; Thompson, 2004). In collaboration with other members of the interprofessional team, nurses can ensure that appropriate planning and implementation of interventions, and on-going monitoring are in place to meet the multidimensional needs of individuals at the end of life.

THE FIVE DOMAINS OF QUALITY END-OF-LIFE CARE (Singer, 1999)

1. Receiving adequate pain and symptom management.
2. Avoiding inappropriate prolongation of dying.
3. Achieving a sense of control.
4 .Relieving burden.
5. Strengthening of relationships with loved ones.

A holistic approach to care and an understanding of individual needs – including physical, social, psychological, existential/spiritual and practical needs – are critical components of quality end-of-life care. These domains are exemplified in the CHPCA's *A Model to Guide Hospice Palliative Care* (Ferris et al., 2002). Studies examining domains of care important to individuals at the end-of-life, have found that although pain and symptom management are important in achieving a good death (Daines, 2004; Miyashita, 2008), avoiding prolonged dying, a sense of control, relationships with others and the relief of burden to others are also important (Singer et al., 1999). Other studies have found that symptom control, continuity of care and reducing caregiver burden are critical elements of care at the end of life (Bernal, Marco, Parkins, Buderer, & Thum, 2007; Tilden et al., 2004).

A GOOD DEATH IS (Leung et al., 2010):

- free from avoidable distress and suffering for patient, family and caregivers;
- in general accord with patient's and family's wishes; and
- reasonably consistent with clinical, cultural, and ethical standards.

However, nurses must be aware that individual needs will vary and are shaped by diverse social, psychological and cultural factors (Dalal, Del Favvro, & Bruera, 2006). Moreover, individuals at the end of life and their families and care team members will have varying levels of understanding, knowledge and skill during each part of the process of providing end-of-life care (Ferris et al., 2002). Therefore, following a comprehensive assessment of individual needs and discussion regarding the goals of care, individualized care planning and subsequent evaluation of outcomes is required. A crucial part of this process is ongoing communication with individuals, their families and other members of the health-care team.

Knowledge and skills regarding how to manage common symptoms experienced by individuals who are nearing the end of their life (e.g. pain, delirium, anxiety, existential distress, nausea and/or vomiting, dyspnea, constipation) can assist nurses in providing quality end-of-life care (Breitbart & Alici, 2008; Claessens, Menten, Schotsmans, & Broeckaert, 2008; Horne-Thompson, 2008; Lanken et al., 2008; Mok et. al., 2010; Qaseem et al., 2008; Thompson, 2004).

Practice Recommendations for Care and Management at the End of Life

RECOMMENDATIONS

RECOMMENDATION

3.1 Nurses are knowledgeable about pain and symptom management interventions to enable individualized care planning.

Type III-IV Evidence

Discussion of Evidence

Research confirms that the use of evidence-informed care strategies for pain, dyspnea and depression can affect individuals' end-of-life experiences (Qaseem et al., 2008). The Cancer Care Ontario (http://cancercare.on.ca/cms/One.aspx?portalId=1377&pageId=58189) and Fraser Health (www.fraserhealth.ca/professionals/hospice_palliative_care/) websites have several evidence-based symptom management guides to practice available, which nurses may find helpful in caring for individuals with cancer and non-cancer diagnoses. The table below are links to guidelines and algorithm for management of specific symptoms.

Symptom	Guide-to-Practice	Algorithm
Pain	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77294 www.rnao.org/Page.asp?PageID=924&ContentID=720	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77292
Delirium	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77276 www.rnao.org/Page.asp?PageID=924&ContentID=797 www.rnao.org/Page.asp?PageID=924&ContentID=818	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77274
Dyspnea	www.cancercare.on.ca/toolbox/symptools	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77280
Anxiety	www.capo.ca/wp-content/uploads/2011/07/ENGLISH_Depression_Anxiety_Guidelines_for_Posting_150611.pdf	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=83160
Nausea Vomiting	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77288	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=77286
Constipation	www.rnao.org/Page.asp?PageID=924&ContentID=809	

Pain

Knowledge of pain and its management across the life span is essential for effective planning and interventions (Delgado-Guay & Bruera, 2008). At the end of life, opioid medications are an integral part of effective pain management. To use these medications effectively, nurses must be knowledgeable about dosing and titration, and be familiar with such issues as tolerance, dependence, addiction and pseudo-addiction (Morrison & Morrison, 2006). The WHO analgesic ladder (www.who.int/cancer/palliative/painladder/en/),

can serve as a guide for nurses in structuring the use of analgesia in the pharmacologic management of pain; however, it is not intended to be a rigid framework. It is important to consider the concept of total pain when assessing individuals.

Delirium

Delirium (also known as terminal restlessness) is a common symptom at end of life, which can cause significant symptom burden and distress to individuals and family members who witness the symptom. Blanchette (2005) found that recognizing and managing terminal restlessness empowers nurses to help individuals achieve a peaceful death and decrease unnecessary distress for the family. It is estimated that 42% of all dying patients experience delirium in the last 48 hours of life (Head & Faul, 2005); thus, it is important that the nurse explains the physiological nature of delirium and potential treatment options to family members (Boyle, 2006; Breitbart & Alici, 2008; Friedlander, Brayman, & Brietbart, 2004).

Dyspnea

Dyspnea is the subjective experience of difficult or uncomfortable breathing, and is a common symptom at the end of life (Tice, 2006; Gallagher, 2003). Dyspnea has been well- documented to have prognostic value. It is often described in terms of air hunger, suffocation, choking, or heavy breathing and is very distressing for family members to witness (Del Fabbro, Reddy, Walker, & Bruera, 2007). To facilitate individualized, family-centered care planning, nurses must maintain current, evidence-based knowledge.

- There is strong evidence to support the use of oral, parenteral or rectal opioids for the management of dyspnea.
- There is insufficient evidence to support the use of nebulized opioids for the management of dyspnea.

(Cranston, Crockett, & Currow, 2009)

Anxiety

Anxiety is another common symptom in individuals diagnosed with a terminal illness. Whether or not the individual has a predisposition to anxiety, it may derive from a variety of sources (Horne-Thompson, 2008; Jackson & Lipman, 2004). Common sources of anxiety at the end-of life include existential distress, fear of pain, pain, fear of death and concern for others (Kissane, 2000; McCoubrie & Davies, 2006; Qaseem et al., 2008; Teunissen et. al., 2007). Existential distress is defined as the experience of life with little or no meaning. It has also been defined as "a state of powerlessness that arises from one's confrontation with one's own mortality and results in the consequent feelings of disappointment, futility and remorse that disrupt one's engagement with and purpose in life" (Kissane, 2000, p.1023). Mok and colleagues (2010) found that existential distress affects the well-being and quality of life of individuals with advanced cancer.

Three causal conditions of existential distress are:

1. Anticipation of a negative future.
2. Failure to engage in meaningful activities and relationships.
3. Having regrets.

(Mok et al., 2010)

The causes of individuals and family members' anxieties must be assessed and addressed, if possible, in order to effectively plan care. This requires collaboration with other members of the interprofessional team and referral where necessary. Health-care professionals, especially nurses, who have frequent contact with individuals, are in a position to address existential issues as part of holistic care. However, a lack of education means that nurses are often ill-prepared to address existential and other psychosocial needs.

Nausea and Vomiting

Nurses need to understand how debilitating and distressing nausea and vomiting can be for individuals and their family members (Thompson, 2004). Nausea and vomiting can have many causes and knowledge of these are essential in both the assessment and identification of appropriate treatment and plans of care (Haughney, 2004). The use of such tools as the ESAS-r (Appendix F) can assist in the assessment and treatment plan for nausea and vomiting.

Constipation

The effect of constipation is often underestimated, yet it can cause a variety of physical symptoms and contribute to restlessness in terminal illness (Goodman, Low, & Wilkinson, 2005; Lanken et al., 2008). Individuals at the end of life are at a high risk of constipation due to decreased food and fluid intake, decreased activity and the side effects of medication. Prevention and prompt treatment are therefore crucial (Mavity, 2006). It should be noted that although aggressive bowel care should be decreased when death is imminent, the body continues to produce solid waste even when food intake is reduced; so, it is important to attend to the individual's need for bowel care until the end of life.

Respiratory Secretions

Respiratory secretions can be quite distressing to family members. Hipp and Letizia (2009) cited a study of 195 bereaved family members and found that 78% of respondents were very distressed by the presence of terminal congestion. The authors also cited a positive correlation between reassurance about this symptom and anxiety. The terms "drowning," "suffocation" and "death rattle" should be avoided in conversations with family; "congestion" may be a more suitable term. Preparing the family for the changes they can expect in the patient's condition as death approaches may be helpful. A combination of both pharmacologic and non-pharmacologic interventions can be used for managing respiratory secretions.

PRACTICE BOX: SYMPTOM MANAGEMENT

- Nurses' knowledge of the assessment and treatment of common symptoms at the end of life will greatly facilitate care planning and promote quality of living and dying.
- Collaborative care planning is central to delivery of quality end-of-life care. A sample collaborative care plan at the end of life is available at the Cancer Care Ontario website (http://cancercare.on.ca/common/pages/UserFile.aspx?fileId=13620).

RECOMMENDATION

3.2 Nurses advocate for and implement individualized pharmacologic and non-pharmacologic care strategies.

Type Ia-IV Evidence

Discussion of Evidence

The provision of interventions through interprofessional collaboration appears to be most effective. A systematic review of 44 studies conducted by Higginson and colleagues (2003) found that interprofessional collaboration had a positive effect on individuals' experiences at the end-of-life. From an interprofessional care perspective, although pharmacologic interventions are important for achieving quality end-of-life care, they may be implemented in conjunction with non-pharmacologic care strategies to facilitate effectiveness (Geoghan, 2008). Several studies have shown that incorporating complementary and alternative medicine (CAM) in end-of-life care delivery provides individuals with a greater perceived sense of control, compared with conventional treatments alone (Ernst, 2009; Davidson, Geoghegan, Mclaughlin, & Woodward, 2005). Similarly, in a systematic

review of 21 studies, Pan and colleagues (2000) found CAM therapies to be effective in improving individuals' comfort near the end-of-life. Based on this review, a summary of evidence and recommendations for CAM use in dying and severely ill patients was developed (Pan et al., 2000). Health-care professionals considering both pharmacologic and nonpharmacologic therapies in caring for this population should be cognizant of the importance of interprofessional collaboration.

RECOMMENDATION

3.3 Nurses educate and share information with individuals and their families regarding:
- reconciliation of medications to meet the individual's current needs and goals of care;
- route and administration of medications;
- potential symptoms;
- physical signs of impending death;
- vigil practices;
- self-care strategies;
- identification of a contact plan for family when death has occurred; and
- care of the body after death.

Type Ib- III Evidence

Discussion of Evidence

The need for decision-making regarding treatment and care is addressed in Section 2, therefore the focus here is on information-sharing with the individual with life-limiting disease as well as any significant others who are involved in their care. Multiple information-sharing strategies have been shown to facilitate understanding of common occurrences at the end of life. These include speaking directly with individuals and their families, written materials and audiovisual resources (Geoghan, 2008).

Information is necessary to prepare family members as caregivers regarding the various roles they may fulfill (Hudson, Hayman-White, Aranda, & Kristjanson, 2006). Family meetings have been found to be a valuable way to raise and address issues, and facilitate linkages to resources (Gueguen, Bylund, Borwn, Levin, & Kissane, 2009). When goals of care are clarified, other challenging topics such as advance care planning, code status, withholding or withdrawing of medical therapies and pertinent medical recommendations may become easier to address (Morrison & Morrison, 2006).

Delirium

An emerging body of evidence confirms the important impact that delirium and changes in cognition can have on individuals at the end of life and families during the last days and hours of life, which may contribute to negative outcomes (e.g. family members may mistake terminal delirium for opioid toxicity and demand that opioid therapy be reduced or discontinued) (Davis, Lasheen, & Gamier, 2007). Family members of a person with delirium have described a sense of "double bereavement", i.e. they grieve the loss of meaningful connection because of the delirium and grieve once again when their loved one dies (Breitbart & Alici, 2008). It is important for the health care team to explain the medical nature of delirium, as well as potential treatment options, including palliative sedation (Breitbart & Alici, 2008). A lack of information about delirium may put family members at risk for complicated grief (Blanchette, 2005). Therefore, educating the family about the dying process and delirium is crucial, and is an ongoing process (Brajtman, 2003; Sagar, 2001).

Dyspnea

Dyspnea is another symptom that has been shown to be very distressing and feared by individuals and families. Explaining the cause of dyspnea and the treatment plan to both individuals and their family is essential. Reassurance that a plan for managing severe dyspnea is in place can lessen the fear of dying in great distress (Gallagher, 2003).

PRACTICE BOX: IMPORTANT INFORMATION TO SHARE WITH INDIVIDUALS AND THEIR FAMILIES (Hudson et al., 2006)

- The emotional toll that caregiving will take.
- The importance of self-care and respite.
- Sharing the caregiver role.
- What to expect as dying approaches.
- How to manage death if it occurs at home.
- When to seek help.
- How to discuss death and dying with the patient.
- Saying goodbye to their loved one.
- The positive aspects of caring.
- Written information and resources.

RECOMMENDATION

3.4 Nurses use effective communication to facilitate end of life discussions related to:

- cultural and spiritual values, beliefs and practices;
- emotions and fears;
- past experiences with death and loss;
- clarifying goals of care;
- family preference related to direct care involvement;
- practical needs;
- informational needs;
- supportive care needs;
- loss and grief; and
- bereavement planning.

Type III Evidence

Discussion of Evidence

Communication about end-of-life issues makes individuals and their families more comfortable and ensures that the goals of care are in agreement with the individual's preferences and circumstances (Gallagher, 2003). When individuals lack the capacity to make decisions, health-care professionals must work with surrogate-decisions makers to determine the appropriate course of action. Decision-making is addressed in Section 2 of this guideline.

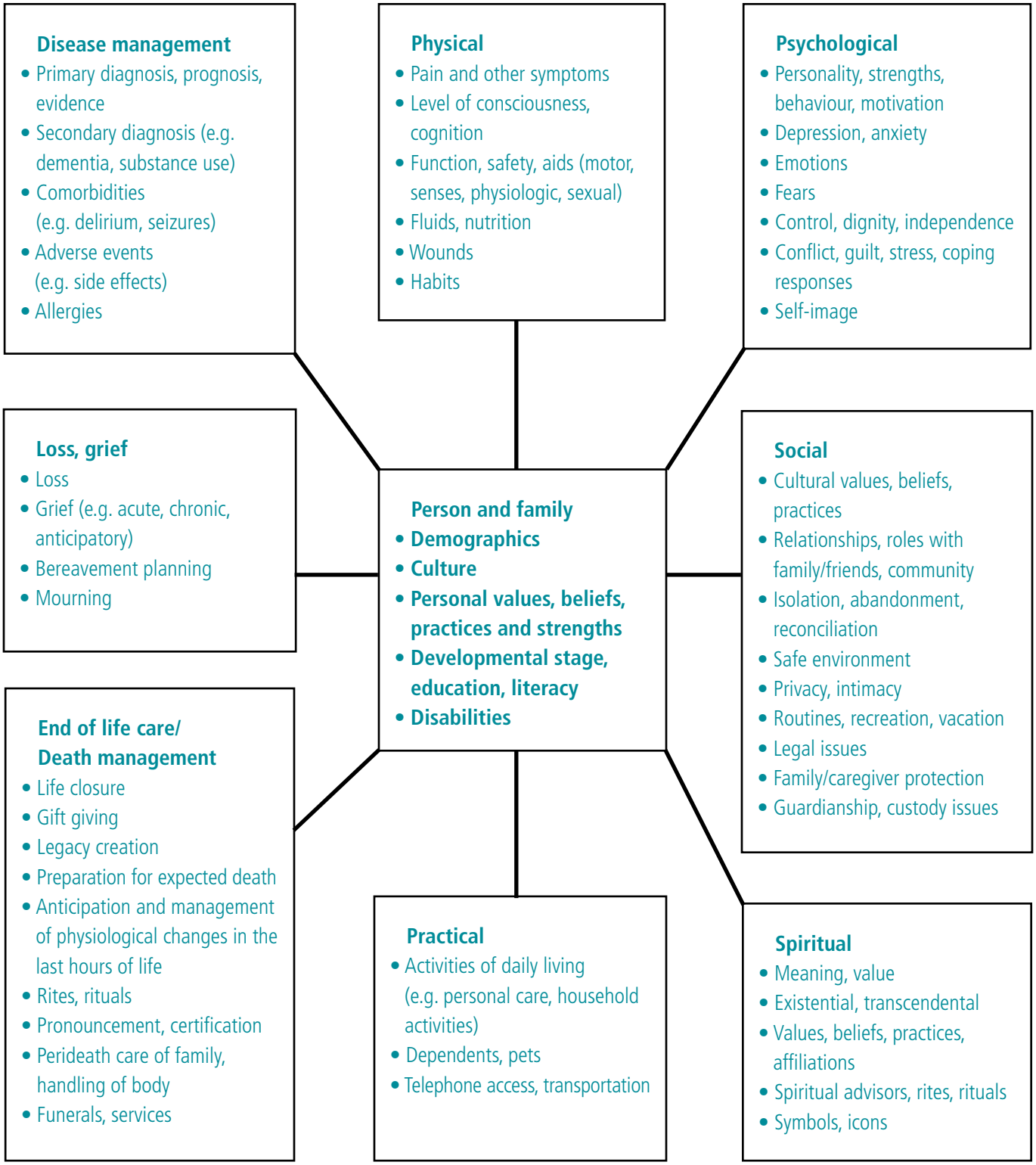
Limitations of the Evidence and Future Directions

Nurses' misconceptions and resultant confusion regarding the intended purposes and effects of medications used at the end of life supports the need for further research on the management of intractable symptoms and suffering in dying patients (Beel, Hawranik, McClement, & Daeninck, 2006; Kohara, Ueoka, Takeyama, Murakami, & Morita, 2005). There is a further need for research to address symptoms specific to the last days and hours of life.

Lin and Bauer-Win (2003) concluded that health-care professionals can play an important role in enhancing psychospiritual well-being, but further research is required to understand specific interventions that are effective and can contribute to positive patient outcomes. Mok et al. (2010) also acknowledges the lack of an accepted conceptual framework of existential distress in patients with advanced cancer. Their work was based on health-care professionals' views; further studies from the perspectives of individuals and their families are needed.

A study by Leung et al. (2010) suggests that individuals have the potential to achieve a good death, if they have the support of an interprofessional palliative care team. Their results require confirmation from future studies that use well-established tools and that are conducted in other patient groups and settings. As Leung and colleagues concluded, factors that may affect the achievement of a good death – patient characteristics, care settings and quality of care – also require further study.

SECTION 4: EDUCATION RECOMMENDATIONS



Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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Education Recommendations

A number of studies have indicated a need for more education in end-of-life care at both the undergraduate and post-registration levels (Betcher, 2010; Brajtman, Higuchi, & Murray, 2009; Brazil & Vohra, 2005; Cooper & Barnett, 2005; DeLoach & Monroe, 2004; Mallory, 2003; Matzo et al., 2003; Meraviglia, McGuire, & Chesley, 2003; Thacker, 2008; Turner et al., 2007). This is not surprising, given the complex care needs of individuals at the end of life and their family members. Evidence suggests that nurses who care for dying individuals across various environments often feel ill-equipped and that they lack the necessary specialized skills, knowledge and competencies required (Betcher, 2010; Holland & Neimeyer, 2005; Thacker, 2008); novice nurses in particular may be challenged due to a lack of clinical experience (Thacker, 2008). Even in settings traditionally associated with end-of-life care, or where exposure to dying and death is fairly common, nurses report a need for education and the development of appropriate skills and competencies (Thacker, 2008; Turner et al., 2007).

Education in end-of-life care is essential for the provision of quality care but it is also critical with respect to nurses' well-being and job satisfaction; nurses who are adequately educated feel more competent in their ability to care for individuals who are dying (Cooper & Barnett, 2005; DeLoach & Monroe, 2004; Holland & Neimeyer, 2005) and experience less fatigue and weariness (Mallory, 2003). A qualitative study of 38 student nurses caring for dying individuals during their first year of education noted many of them expressed feelings of inadequacy, which further led to considerable anxiety (Cooper & Barnett, 2005).

KNOWLEDGE AND SKILLS INTO PRACTICE (KNOWLEDGE TRANSLATION) (Graham, et al., 2006)

Education informed by the best available evidence is one component necessary for quality end-of-life care. The process of translating knowledge and skills into the practice environment is challenging and requires consideration of the context of care and the knowledge content. Approval of stakeholders and organizational* level support are crucial to the adoption of knowledge.

**Organizational and policy recommendations are discussed in Section 5*

Education recommendations 4.1 and 4.2 identify the content, structure and process of end-of-life education as a means to facilitate adoption at the undergraduate and post-registration levels. Omitted in the recommendations is specialized education aimed at nurses practiced in palliative care. Nurses interested in formal palliative care education as a specialty, should refer to the CHPCA website (www.chpca.net) and the Canadian Nurses Association (www.cna-nurses.ca).

We are mindful in making these recommendations that there must be awareness by organizations of the need for continuing professional development opportunities for end-of-life care and policies in place to support their adoption. In a survey of theory and clinical educators, Brajtman and colleagues (2009) identified several factors that influence the dept and breadth of end-of-life education at the undergraduate level, including overloaded undergraduate curriculum and lack of formal planning to integrate the content into the curriculum. Educators and curriculum developers must therefore recognize the importance of end-of-life care in preparing future nurses and be creative in adapting end-of-life content into both core and specialized courses. Indeed, there is evidence to support the integration of end-of life care into the undergraduate curriculum in the United States, as proposed by the End of Life Nursing Education Consortium (www.aacn.nche.edu/elnec) (Ferrell et al., 2005; Kurtz & Hayes, 2004; Wallace et al., 2009; Whitehead, Anderson, Redican, & Stratton, 2010). Certainly, integrating end-of-life care into core courses such as gerontology, pediatrics, medical and surgical nursing and trauma will ensure that educational content addresses the specific needs of particular populations.

Educators' personal learning needs may also influence end-of-life education. Brajtman et al. (2009) found that although educators had positive attitudes toward dying and death, their knowledge was modest. Educators lacking in the knowledge, skills and experience to teach end-of life care may refer to the various palliative care resources available (see Appendix L).

At the post-registration level, one of the main barriers to education in end-of-life care is organizational support (Caton & Klemm, 2006). Research indicates that although organizations may be encouraging, a lack of release time from work, costs, location and staff shortages prevent many from actually attending (McDonnell et al., 2009). Recognition of nurses' professional development must be made a priority, to ensure that individuals receive quality end-of-life care and that nurses feel adequately prepared to provide this care.

Strong collaborative relationships between nurses in academic and clinical settings may facilitate the exchange of specialized palliative care knowledge and development of competencies. However, this approach has not yet been validated.

RECOMMENDATION

4.1 Entry to practice nursing programs and post-registration education incorporate specialized end-of-life care content, including:

- dying as a normal process including the social and cultural context of death and dying, dying trajectories and signs of impending death;
- care of the family (including caregiver);
- grief, bereavement and mourning;
- principles and models of palliative care;
- assessment and management of pain and other symptoms (including pharmacologic and non-pharmacologic approaches);
- suffering and spiritual/existential issues and care;
- decision-making and advance care planning;
- ethical issues;
- effective and compassionate communication;
- advocacy and therapeutic relationship-building;
- interprofessional practice and competencies;
- self-care for nurses, including coping strategies and self-exploration of death and dying;
- end-of-life issues in mental health, homelessness and the incarcerated;
- the roles of grief and bereavement educators, clergy, spiritual leaders and funeral directors; and
- knowledge of relevant legislation.

Type Ia-III Evidence

Discussion of Evidence

From the available literature, it appears that certain content is essential to educating nurses regarding end-of-life care, and this content reflects the CHPCA's A Model to Guide Hospice Palliative Care (Ferris et al., 2002) and the Canadian Nurses Association core competencies in hospice palliative nursing care (CNA, 2003).

Caring is a cornerstone of nursing. Effective and therapeutic communication is a critical aspect of conveying caring in practice and also for understanding the needs of individuals and their families at the end of life, planning and implementing nursing care and advocacy (Kennedy-Sheldon et al., 2006). A number of studies have demonstrated that certain types of communications (i.e. spiritual and emotional discussions, dealing with families and discussions regarding treatment and decision-making) can be particularly difficult for nurses (Heaston et al., 2006; Kennedy-Sheldon et al., 2006; McMillen, 2008; Shih et al., 2006). Nurses have also expressed a need for more training in communication skills (Betcher, 2010; Matzo, Sherman, Sheehan, Ferrell, & Penn, 2003). There is ample evidence to support education in communication skills (Turner et al., 2009; Wilkinson et al., 2008). Wilkinson et al. (2008) in a multi-site, two-arm, randomized controlled trial regarding nurse and patient outcomes found that communications skills training improved patient satisfaction and enhanced nurses' confidence, communication and emotional state. These changes persisted at 12 weeks post-training.

Caring for individuals near the end of life can present unique challenges regarding decision-making, advance directives and ethical issues (Heaston et al., 2006). Guidance and an understanding of factors that may influence this process, in addition to an exploration of ethical issues, should be part of end-of-life care training. Decision-making and ways to support individuals through this process is detailed in Section 2 of this guideline.

There is strong evidence to support educational interventions aimed at building skills in decision support that result in higher-quality patient decision support (Murray et al., 2009; Stacey et al., 2006). In a non-randomized trial undertaken to evaluate an intervention designed to help nurses support patient decision-making, approximately one-half of participants felt they were unable to uphold individuals' wishes and experienced job dissatisfaction due to perceived inappropriateness of the level of care delivered prior to the intervention. Following the intervention, nurses were better able to effectively advocate for patient involvement in decision-making and perceived that when individuals were empowered to exercise self-determination, care was more satisfying and consistent with patient preferences (Marion, 2007). Specific teaching in advocacy and end-of-life care has also been shown to increase nurses' advocacy behaviours in clinical practice (Thacker, 2008).

Since the underlying philosophical approaches to palliative care differ from traditional curative approaches, an understanding of these principles is fundamental. Principles of palliative care should be included in the nursing education undergraduate curriculum and also be available as continued professional education. Since dying and death occur within a social and cultural context, these concepts should be incorporated into educational programs, to ensure that the care provided respects individuals' needs, wishes, beliefs and values. The illness trajectory should also be included in educational initiatives, as research has shown that nurses would also like specific education regarding care of individuals during the last days and hours of life (Wallace et al., 2009).

The CHPCA recognizes the importance of an interprofessional approach to end-of-life care; although access to specialist health-care providers will vary depending on the circumstances and context, an understanding of the roles of other health-care providers and the team approach should be part of end-of-life care education (Ferris et al., 2002). Research to support interprofessional end-of-life care educational initiatives is sparse, but there is some research to indicate that improvements in health-care providers' awareness of the roles and contributions of interprofessional team members can be made (Brajtman et al., 2009). Furthermore, there is support for interprofessional education in other areas of health care (Remington et al., 2006).

Given the prevalence of pain and other symptoms at the end of life (Klinkenberg et al., 2004; Kutner et al., 2001) (covered in Section 1 and Section 3), the assessment and management of symptoms – including pharmacologic and non-pharmacologic approaches – should be integral to nurses' education. This education should go beyond the physical aspects, and incorporate psychosocial aspects and spiritual/existential distress (Cooper & Barnett, 2005; Morita et al., 2006; Shih et al., 2006; Wallace et al., 2009). In a study of 147 nurses in Japan, Morita and colleagues (2006) found that training aimed at improving nurses' skills resulted in significant improvements in nurses' perceived practice attitudes and confidence in dealing with dying individuals who were experiencing feelings of meaningless.

Care of the dying means more than care for the individual facing the end of life; it also extends to family. Thus, education should incorporate family members' responses, including the impact of caregiving, an understanding of grief and bereavement and how to support the family (Wallace et al., 2009). Recognition of individuals who may benefit from referral to specialized health-services (e.g. counseling, pastoral care) is key to ensuring the health and well-being of family members.

Content related to nurses' own beliefs and values – and exploration of their attitudes toward dying and death – is fundamental as nurses' anxieties about death could influence the care provided (Cooper & Barnett, 2005; Deffner & Bell, 2005; Ferrell et al., 2005; Halliday & Boughton, 2008; Kennedy-Sheldon et al., 2006; Mallory, 2003; Matzo et al., 2003). The evidence demonstrates that training directed toward dying and death is effective in reducing death anxiety (Halliday & Boughton, 2008; Whitehead et al., 2010). Indeed, an understanding of one's own beliefs about dying and death and education in self-care, including coping techniques, is important for preparing nurses to care for the dying, as the emotional and physical demands make nurses particularly vulnerable to burnout and stress (Keidel, 2002; Sandgren et al., 2006). Education in end-of-life care has been shown to reduce aspects of burnout and anxiety about death (Halliday & Boughton, 2008; Holland & Neimeyer, 2005; Kwekkeboom & Eland, 2005; Mallory, 2003).

Limitations of the Evidence and Future Directions

Few studies have examined the content of end of life education and its relationship to quality end-of-life care (Morita et al., 2006; Thacker, 2008; Wilkinson et al., 2008). Instead, much of the published research involves surveys, evaluations or qualitative studies whereby nurses' preferences for particular content are sought (Wallace et al. 2009), or descriptive comparative studies where attitudes and/or knowledge are examined (Brajtman, 2009; Cooper & Barnett, 2005; Halliday & Boughton, 2008; Morita et al., 2006; Wallace et al., 2009). Although there is a range of evidence to support this recommendation, the majority of the evidence is weak. When considering the evidence, it is important to understand the limitations of individual studies, since the validity of the findings may be affected, e.g. the use of self-report for changes in such outcomes as behaviour and attitudes, perceived knowledge and skills (Morita et al., 2006; Thacker, 2008; Whitehead et al., 2010) and small sample sizes in quantitative studies (Kurtz & Hayes, 2004; Whitehead et al., 2010).

An added issue is inconsistency in the types and/or amount of content included, e.g. some studies focus on particular aspects of end-of-life care education, such as communication skills training, education on dying and death, and dealing with dying individuals' feelings of meaningless (Morita et al., 2006; Turner et al., 2009; Wallace et al. 2009), while others include a combination of end-of-life content, making it difficult to discern the most informative content.

RECOMMENDATIONS

RECOMMENDATION

4.2 Successful education in end-of-life care includes specific attention to the structure and process of learning activities and incorporates:

- small group learning;
- dyadic and experiential learning approaches;
- integration and consolidation of theory and practice;
- opportunities to practice the skills and competencies acquired;
- constructive feedback and/or reflection on acquired knowledge, skills and competencies; and
- contact with knowledgeable and supportive clinical supervisors and mentors.

Type Ib-III Evidence

Discussion of Evidence

A variety of strategies for education in end-of-life care have been studied, alone or in combination, including observation and clinical practice in palliative care settings, reflective practice, problem-based learning (whereby case studies are used to address particular issues relevant to individuals who are dying), vignettes, seminars and lectures, online learning, multi-media, role play, laboratory skills training, literature review, simulation and reflection (Cooper & Barnett, 2005; Holland & Neimeyer, 2005; Kwekkeboom & Eland, 2005; Turner et al., 2009; Wallace et al., 2009; Whitehead et al., 2010; Wilkinson et al., 2008). Most studies included a combination of approaches, however, a key feature is the use of a combination of didactic and experiential learning, whereby students had an opportunity to actively engage, as well as critically evaluate and generalize from the knowledge gained.

Given the diversity in the structure and process of teaching, it is difficult to determine which approaches are most effective. However, a consistent finding across a range of studies examining nurses' preferences indicated that small-group learning sessions that encouraged reflection and where specialist skills are taught, and theory as well as practice are integrated, are preferred (Cooper & Barnett, 2005; Holland & Neimeyer, 2005).

The research further highlights the need for consolidation of the knowledge taught with an opportunity to practice in palliative care settings and develop specialist skills (Cooper & Barnett, 2005; Holland & Neimeyer, 2005). This type of hands-on experience as part of clinical placements – with the support of clinical supervisors and an opportunity to reflect on the experience and express reactions – appears to be important to student nurses in dealing with anxieties about death and the dying individual and his/her family (Halliday & Boughton, 2008; Kurz & Hayes, 2004). For novice nurses, mentoring from more experienced nurses, with the opportunity to develop competencies using ancillary materials, may be an effective strategy (Caton & Klemm, 2006).

Interactive approaches have been shown to be the preferred method for developing communication skills and for developing relationships (Turner et al., 2009; Wallace et al., 2009; Wilkinson et al., 2008). Wilkinson and colleagues (2008) noted improvements in nurses` knowledge and confidence in communicating with individuals with cancer who were receiving palliative care, following a three-day communication skills program. The program emphasized experiential learning and included a didactic lecture on communication techniques and role-playing during simulations of end-of-life scenarios. Constructive feedback helped nurses analyze and improve their performance. In this study, gains from the communication skills program were sustained at three months follow-up. Furthermore, individuals who were interviewed by nurses who received the communication skills training program, had a more positive general emotional state and were more satisfied with the communication, than those interviewed by nurses who were in the control group (Wilkinson et al., 2008).

With advances in internet-based technologies, online learning programs and internet resources are increasingly being used (Kavanaugh et al., 2009; Tieman & Rawlings, 2008); to date, there is little evidence to support the effectiveness of these approaches, although student feedback in online course evaluations has been positive (Kavanaugh et al., 2009), and research on the utility and credibility of online resources shows promise (Tieman & Rawlings, 2008).

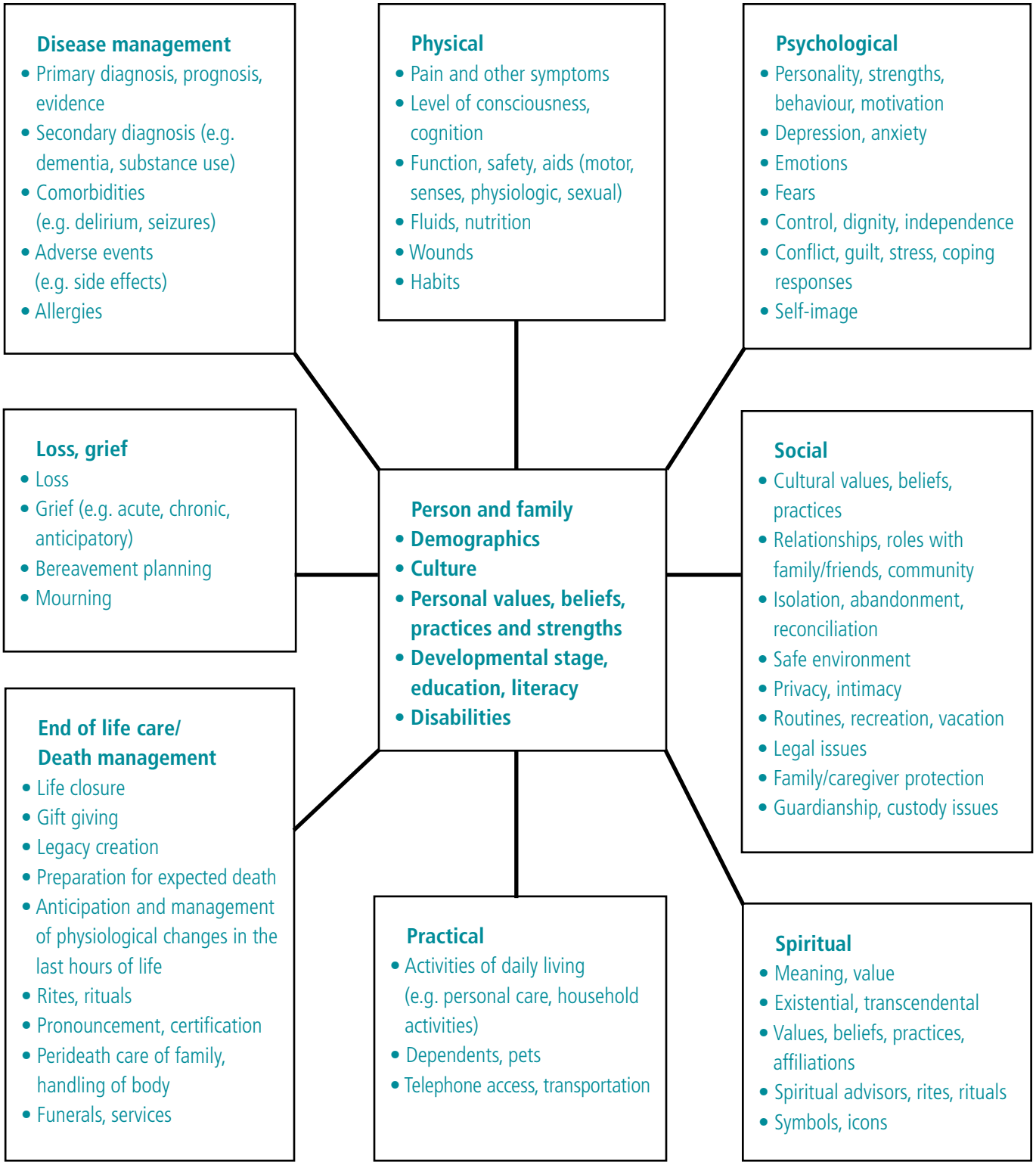
Research on the timing and amount of education in end-of-life care is sorely lacking. There is general agreement that core end-of-life care competencies should be developed at the undergraduate level but determining when to commence this education and whether it should consist of one or more dedicated courses, clinical placements or integrated across the curriculum is not known. If clinical placements begin early in the undergraduate nursing curriculum, then students may face dying and death unprepared if education is not provided beforehand. However, as Mallory (2003) points out, if education on end-of-life is provided too early then students may not relate to the information due to a lack of experience. Finally, research indicates that ongoing training may be necessary (Kurtz & Hayes, 2004), to ensure that nurses' knowledge and skills remain relevant, and that they develop new skills as appropriate.

Limitations of the Evidence and Future Directions

Despite some innovative approaches to integrating end-of-life care into baccalaureate nursing programs, lack of consistency in the amount, content, and teaching and evaluation strategies make specific recommendations difficult to advocate. Furthermore, at both the undergraduate and post-registration level, a lack of formal evaluation has made it difficult to advocate for various approaches (Brajtman et al., 2009; Kavanaugh et al., 2009). Educational program developers should consider integrating formal evaluation into the development and implementation of educational programs, to identify the most relevant content and structure, and effective teaching strategies.

The research evidence is generally weak in this area; few studies have taken a longitudinal approach (Kurtz & Hayes, 2004; Whitehead et al., 2010; Wilkinson et al., 2008) to examine whether changes as a result of education are sustained over time. Noteworthy is the lack of research linking education to nursing competencies and quality end-of-life care outcomes such as pain and symptom management, and satisfaction with care. Future research regarding the aforementioned limitations should be undertaken.

SECTION 5: ORGANIZATION AND POLICY RECOMMENDATIONS



Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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Organization and Policy Recommendations

While both challenging and rewarding, repeated exposure to suffering, grief and losses associated with end-of-life care is a potential stressor for nurses. Unfortunately, little is known about nurses' subjective experiences when providing care to individuals and their families at the end of life. In an investigation into emotional work, emotional well-being and professional practice of generalist community nurses, it was found that attention to the issues that either limit or enhance the emotional well-being of nurses was critical, as was the development of self-care strategies (Glass & Rose, 2010).

It is well-documented that providing end-of-life care is stressful for providers; however, there is little published evidence to guide recommendations for strategies for employers and nurses. What is known is included in the recommendations in this section. Supportive organizational behaviours include implementing models of care delivery that support continuity of the nurse-individual-family relationship, recognizing nurses' well-being as a valued asset to organizations providing end of life care and developing responsive strategies and using the A Model to Guide Hospice Palliative Care (Ferris et al., 2002) to guide the development of palliative and end-of-life care services.

In addition to the need for organizational structures and processes to support nurses to balance their personal and professional commitments to the provision of end-of-life care, nurses themselves and the nursing profession also must ensure their awareness and practice of self-care strategies to maintain a positive work-life balance.

RECOMMENDATION

5.1 Models of care delivery support the nurse, individual and family relationship.

Type III-IV Evidence

Discussion of Evidence

Each year, more than 248,000 Canadians die (CHPCA, 2004), the majority of them in institutions; yet, there is currently no evidence to support an ideal nursing model or nurse to client ratio for the care of imminently dying individuals and their families. This must be better understood in order for the nursing profession to respond to the needs of dying individuals and their families across health-care settings.

Attending to the needs of the dying individual and his/her family has been demonstrated as a highly valued indicator of quality nursing care by bereaved family members (Brazil, Bainbridge, Sussman, Whelan, O'Brien & Paytte, 2009). Continuity of care is critical to supporting the individualized needs of patients and their families during the last days and hours of life (Aiken et al., 2001; O'Brien-Pallas, Duffield & Alksnis, 2004; Pringle & Doran, 2003). Nursing case loads and assignments that reflect individual client complexity and availability of resources facilitate quality care during the last days and hours of life. It has been noted that models of care delivery that support continuity of care produce greater nurse, client and family satisfaction (Brazil et al., 2009; Forbes-Thompson & Gassert, 2005).

A model of nursing care delivery that supports continuity of care will facilitate the development of nurse, client and family therapeutic relationships. The RNAO best practice guideline Establishing Therapeutic Relationships (RNAO, 2006) is a recommended resource for nurses, nurse leaders and decision-makers who are interested in implementing and evaluating effective models of care delivery.

RECOMMENDATION

5.2 Organizations recognize that nurses' well-being is a critical component of quality end-of-life care and adopt responsive strategies.

Type III-IV Evidence

Discussion of Evidence

Providing end-of-life care can be a highly rewarding experience for nurses in any setting. However, the physical, emotional, spiritual and psychological demands of caring for individuals experiencing life-limiting illness and their families, coupled with exposure to constant suffering, loss and grief, increases nurses' risk for compassion fatigue, burnout and physical illness (Glass & Rose, 2010; York, Jones, & Churchman, 2009).

ATTRIBUTES OF A HEALTHY WORK ENVIRONMENT THAT SUPPORT NURSES PROVIDING END-OF-LIFE CARE

(DeLoach & Monroe, 2004; Heaston, Beckstrand, Bond, & Palmer, 2006)

- Contribution to organization and patient/family.
- Practice autonomy.
- Positive interprofessional collaboration.
- Adequate resources and time to perform activities.
- Look forward to going to work.
- Learning/challenging environment.
- Positive emotions.
- Financial reward and positive feedback.
- Supportive supervisors.
- Quality communication between nurses and physicians.
- Physical environment design to support privacy.

York et al. (2009) studied the association between employee satisfaction and family perceptions of quality of care in hospice service delivery. Their study demonstrated that in order to attract and retain a highly skilled, motivated and healthy nursing workforce, there is a need for organizations to support nurses to develop skills in self-care and to attend to nurses' role satisfaction. Similarly, DeLoach and Monroe (2004) studied job satisfaction among hospice workers and noted that job satisfaction included having task significance, supervisory support, integration, distributive justice, positive affectivity, autonomy, routinization, no role overload and high levels of work motivation. Specifically, working with individuals and families and carrying out the hospice philosophy, being comfortable with their level of knowledge and skills, and having good relationships with team members played a significant role in their degree of job satisfaction.

SELF-CARE STRATEGIES TO ASSIST NURSES IN PROVIDING PALLIATIVE CARE

(DeLoach & Monroe, 2004; Jalyn & Glass, 2010)

- healthy lifestyle choices;
- debriefing;
- self-validation;
- assertiveness;
- emotional support;
- team skills; and
- developing supportive relationships.

Workplace health and safety for nurses is essential to achieving organizational outcomes. When workplaces are supportive, nurses are less likely to leave palliative and end-of-life care to seek opportunity elsewhere. The RNAO's (2008) Healthy Work Environments best practice guideline entitled *Workplace Health, Safety and Well-being of the Nurse* is an excellent resource to guide organizations in a systematic approach to integration of wellness into the workplace culture and climate.

The promotion of workplace wellness and safety requires education regarding burnout among hospice palliative care professionals in end-of-life care settings. A study conducted by Holland & Neimeyer (2005) regarding the concept of burnout in palliative care settings revealed that participants who had more end-of-life care education experienced less physical fatigue and cognitive weariness but were not necessarily less exhausted emotionally. As such, work environments should allow for and encourage spiritual expression among staff, including memorial services and rituals that promote diversity of spiritual expression. It is also important that end-of-life care education focus on nurses' emotional needs by offering information on starting support groups, responding to bereaved coworkers and normalizing grief experienced after the loss of a patient.

RECOMMENDATION

5.3 Organizations providing end-of-life care demonstrate evidence of a philosophy of palliative care based on the Canadian Hospice Palliative Care Association's The Model to Guide Hospice Palliative Care.

Type III-IV Evidence

Discussion of Evidence

The CHPCA's *A Model to Guide Hospice Palliative Care* is the Canadian framework that serves to guide development and evaluation of new or existing hospice palliative care programs and services. The model sets out principles, norms of practice, domains of issues and a shared vision for hospice palliative care that supports organizations in assessing adherence and structuring quality improvement initiatives. A useful tool to facilitate this process is the Square of Care and Organization, which is contained within *A Model to Guide Hospice Palliative Care* (Appendix J).

There is a growing body of evidence that identifies the gap in knowledge and skills of health-care professionals and the end-of-life care needs of their patients (Brazil & Vohra, 2005; Heaston et al., 2006; Kurtz & Hayes, 2006). These are identified in Section 4 of this guideline. Organizations can use *A Model to Guide Hospice Palliative Care* to identify education and professional development opportunities and organizational supports that care providers need in order to provide high-quality end-of-life care. This may include initial orientation and ongoing educational programs that support knowledge and skill development. The model can be used to help manage programs and services, as well as help organizations determine the resources required (Ferris et al., 2002). It can also serve as a foundational document for policy development and program evaluation.

When using the model for the purpose of developing or evaluating hospice palliative care programs and services, organizations are encouraged to use existing tools and planning frameworks. One such tool is the Toolkit of Instruments to Measure End-of-life Care (TIME) (available at www.chcr.brown.edu/pcoc/toolkit.htm). The Toolkit can serve as a measurement tool to allow organizations to identify opportunities for and barriers to improvement of end-of-life care delivery.

RECOMMENDATION

5.4 Nursing best practice guidelines can be successfully implemented only when there are adequate planning, resources, organizational and administrative supports, as well as appropriate facilitation. Organizations may wish to develop a plan for implementation that includes:

- An assessment of organizational readiness and barriers to implementation.
- Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process.
- Dedication of a qualified individual to provide the support needed for the education and implementation process.
- Ongoing opportunities for discussion and education to reinforce the importance of best practices.
- Opportunities for reflection on personal and organizational experience in implementing guidelines.

In this regard, a panel of nurses, researchers and administrators developed the Toolkit: *Implementation of Clinical Practice Guidelines* (2002) based on available evidence, theoretical, perspectives and consensus. The toolkit is recommended for guiding the implementation of the RNAO guideline *End-of-Life Care During the Last Days and Hours*.

Type IV Evidence

Discussion of Evidence

A critical initial step in the implementation of guidelines is their formal adoption and evaluation. Organizations must consider how to formally incorporate the recommendations to be adopted into their policy and procedure structure (Graham, Harrison, Brouwers, Davies & Dunn, 2002). One example of such a formal adoption is the integration of the guideline into existing policies and procedures. This initial step paves the way for general acceptance and integration of the guideline into the quality management process.

A commitment to monitoring the impact of the implementation of the *End of Life Care During the Last Days and Hours* best practice guideline is a key step that must be taken if there is to be an evaluation of the impact of the efforts associated with implementation. It is suggested that each recommendation to be adopted be described in measurable terms, and that the health-care team be involved in the evaluation and quality monitoring processes. A suggested list of evaluation indicators is provided on page 62.

New initiatives, such as the implementation of a best practice guideline, require strong leadership from nurses who are able to transform the evidence-based recommendations into useful tools that will assist in directing practice. In this regard, the RNAO (through a panel of nurses, researchers and administrators) has developed the *Toolkit: Implementation of Clinical Practice Guidelines* (2002) based on available evidence, theoretical perspectives and consensus. The toolkit is recommended for guiding the implementation of the RNAO best practice guideline *End-of-Life Care During the Last Days and Hours*. Appendix M provides a description of the toolkit.

Limitations of the Evidence and Future Directions

With demands for access to high-quality end-of-life care increasing across settings and across illness trajectories, it is critical that the issues that both limit and enhance nurses' willingness and ability to engage in and remain in this area of practice be understood.

While there is ample evidence to support the need for healthy work environments for nurses, specific strategies and recommendations to address the unique needs of nurses who provide end-of-life care are in their infancy. More research is required in order to understand and analyze the experience of nurses providing end-of-life care in all settings.

It is recommended that studies articulating the enablers and barriers for nurses to provide professional end-of-life care that balances cognitive, emotional, psychological and spiritual nursing work are undertaken. Futures directions should include development of a conceptual model and framework to guide the articulation and implementation of micro, meso and macro organizational and policy initiatives.

Research Gaps and Future Implications

As outlined in each section, the development panel, in reviewing the evidence during the development of this guideline, has identified several gaps in the research literature related to end-of-life care during the last days and hours.

The issues identified below, although in no way exhaustive, represent an attempt to identify and prioritize the research gaps in this area. Some of the recommendations in this guideline are based on evidence gained from qualitative or quantitative research, while others are based on consensus, reports or expert opinion. Further substantive research is required in some areas to validate the expert opinion and impact knowledge that will lead to improved nursing practice and outcomes related to end-of-life care during the last days and hours.

Assessment

- Standardization of assessment tools at the end of life.
- Validation of assessment tools for different diseases.
- Disease specific prognostic models to predict the end of life.
- Physical basis for terminal symptoms.
- Impact of support on bereavement outcomes.
- Impact of nurse's communication regarding imminent death on family experience and emotional coping.

Decision Support

- When and how to engage substitute decision-makers while respecting the individual's autonomy.
- How to best facilitate knowledge transfer and sharing outcomes of decision-making discussions among team members and other stakeholders.
- Link between how an individual's participation in decision-making affects individual and system outcomes.

Intervention

- Management of intractable symptoms and suffering in the dying patient.
- Specific interventions for enhancing psychospiritual well-being.
- Randomized studies to support various interventions during the last days and hours of life.
- Factors that may affect the achievement of quality of life and a good death, including patient characteristics, care settings and quality of care.
- Conceptual framework of existential distress for individuals with cancer or non-cancer diagnoses.

Education

- Approaches for integrating formal evaluation into the development and implementation of end-of-life educational programs.
- Linking education to nursing competencies and quality end-of-life care outcomes such as pain and symptom management and satisfaction with care.

Organization/Policy

- Issues that limit and enhance nurses' willingness and ability to engage in and remain in palliative care area of practice.
- Strategies and recommendations to address the unique needs of nurses who provide end-of-life care.
- Enablers and barriers for nurses to provide professional end-of-life care that balances cognitive, emotional, psychological and spiritual nursing work.
- Development of a conceptual model and framework to guide the articulation and implementation of micro, meso and macro organizational and policy initiatives.

Evaluation/Monitoring of Guideline

Organizations implementing the recommendations in this nursing best practice guideline are advised to consider how the implementation, and its impact, will be monitored and evaluated. The following table, based on a framework outlined in the RNAO *Toolkit: Implementation of Clinical Practice Guidelines* (2002), illustrates specific indicators for monitoring and evaluation of the guideline.

Level of Indicator	Structure	Process	Outcome
System	Support for individuals and families in the last days and hours of life is included across the health care continuum.	Advocacy for increased support for quality end-of-life care within health-care organizations. Environment supports health-care professionals in providing quality end-of-life care.	Increased understanding, acceptance of and level of support for quality end-of-life care in Canada.
	Nursing education programs embed theoretical and practical concepts related to end-of-life care within the curricula.	Ongoing dialogue between Schools of Nursing and palliative/ hospice care association and organizations.	Enhanced partnerships between Schools of Nursing and organizations offering palliative/hospice care services.
Organization	Nurses have access to validated tools and other resources that will be used in the assessment of individual/family needs.	Nurses use validated tools as part of a comprehensive assessment for individuals and families in the last days and hours of life.	Nurses possess the knowledge and skills to identify and provide quality care for individuals and families in the last days and hours of life. Nurses possess the knowledge, skills and tools to perform a comprehensive assessment of the individual/family unit.
	Nurse to patient ratios are appropriate to allow individualized care for the individual and their family in the last days and hours of life.	Workload measurement tools are in place and used appropriately to plan staffing.	Organizational outcomes such as: • Turnover rates • Sick time •Retention rate
	Interprofessional team members are available to assist in providing appropriate care (e.g. spiritual care, social work, specialized palliative care consultation).	There is a clearly defined organizational mechanism for nurses to access the interprofessional team.	Nurses recognize and communicate the signs and symptoms of impending death to the team and the family.

Level of Indicator	Structure	Process	Outcome
	Policies and procedures are in place at the organizational level to support nurses in providing evidence-based end-of-life care.	Nurses, interprofessional teams and individuals/families are involved in the creation of policies. Develop partnerships between organization offering hospice/palliative care services. Develop strategy to evaluate the changes in practice that lead to improved end-of-life care.	Evidence that policies and procedures related to best practice strategies are consistent with this guideline. Evidence of interprofessional approach in policy and procedure development. Improved collaboration between organizations Evaluation process in place that examines end-of-life care outcomes Evidence of improved individual/family care outcomes (i.e. satisfaction, assessment and management of symptoms, level of support for end-of-life care decisions, etc.).
Nurse	Education related to caring for individuals at the end of life (last days and hours) is available in each care setting Nursing orientation includes education regarding end-of-life care and management.	Nurses complete a comprehensive assessment of individual and family in the last days and hours of life. Nurses document effect of end-of-life care interventions.	Number of nurses attending educational sessions. Completion of educational programs related to end-of-life care. Evidence of documentation in health records consistent with BPG recommendations regarding: • Assessment • Decision support • Management
	Nursing leadership	Development of opportunities in end-of-life/palliative care mentorship and leadership roles.	Increased number of nurse preceptors in palliative/hospice care programs. Increased number of nurses applying for the RNAO's Advanced Clinical Practice Fellowship Program focused on end-of-life care.

Level of Indicator	Structure	Process	Outcome
	Nurses and non-nursing staff with theoretical and practical knowledge of sound end-of-life care approaches.	Nurses and non-nursing staff identify their learning needs or proportion of nurses demonstrating personal reflection on the application of required knowledge and skills in working with individuals and families in the last days and hours of life. Nurses champion and promote the utilization of this best practice guideline in their daily practice. Nurses' and non-nursing staff's self assessed knowledge of the importance of: • Collaboration with interprofessional team, individuals and families in promoting effective end-of-life care. • The use of theory to guide end-of-life care practices.	Completion of educational programs related to strategies and approaches for delivering effective end-of-life care. Percent of nursing and non-nursing staff who report being actively involved in the implementation process. Nurses apply theory and evidence to their practice with individual and family as partners in end-of-life care delivery.
Client	Individuals/ families have access to reliable and evidence-based information to inform their decisions.	Individuals/families verbalize to their health-care providers uncertainties regarding end-of-life care decisions. Individuals/families are provided with reliable, evidence-based information and validated tools to guide decision-making processes related to end-of-life care.	Rationale for not proceeding with the chosen treatment is documented. Documentation of advanced directives in the health record. Documentation of individual's/family's degree of confidence with decision in the health record.
	Individuals have access to health-care providers with knowledge and skills in end-of life care strategies.	Individual/families collaborate in end-of-life care planning and management.	Individual/family satisfaction with care received. Seamless care.
Financial Costs	Provision of adequate financial and human resources for guideline implementation.	Development of evaluation process for resource allocation. Creation of partnerships/ strategies for cost-sharing. Process is created for inclusion of stakeholders regarding resource allocation. Costs for education, other interventions and on-the-job support.	Optimal investment of resources related to the care of individuals/families in the last days and hours of life. Overall resource utilization (identify organizational specific, new staff hires. etc.).

Implementation Strategies

The Registered Nurses' Association of Ontario and the guideline development panel have compiled a list of implementation strategies to assist health-care organizations or health care providers that are interested in implementing this guideline. A summary of these strategies follows:

- Have at least one dedicated person, such as an advanced practice nurse or a clinical resource nurse, who will provide support, clinical expertise and leadership. The individual should also have good interpersonal, facilitation and project management skills.
- Conduct an organizational needs assessment related to end-of-life care to identify current knowledge base and future educational requirements.
- Initial needs assessment may include an analysis approach, survey and questionnaire, group format approaches (e.g. focus groups), and critical incidents.
- Establish a steering committee composed of key stakeholders and interdisciplinary members who are committed to leading the change initiative. Identify short- and long-term goals. Keep a work plan to track activities, responsibilities and timelines.
- Create a vision to help direct the change effort and develop strategies for achieving and sustaining the vision.
- Program design should include:
  - target population;
  - goals and objectives;
  - outcome measures;
  - required resources (human resources, facilities, equipment); and
  - evaluation activities.
- Design educational sessions and ongoing support for implementation. The education sessions may consist of presentations, facilitator's guide, handouts, and case studies. Binders, posters and pocket cards may be used as ongoing reminders of the training. Plan education sessions that are interactive, include problem-solving, address issues of immediate concern and offer opportunities to practice new skills (Davies & Edwards, 2004).
- Provide organizational support such as having the structures in place to facilitate the implementation. For example, hiring replacement staff so participants will not be distracted by concerns about work and having an organizational philosophy that reflects the value of best practices through policies and procedures. Develop new assessment and documentation tools (Davies & Edwards, 2004).
- Identify and support designated best practice champions on each unit to promote and support implementation. Celebrate milestones and achievements, acknowledging work well done (Davies & Edwards, 2004).
- Organizations implementing this guideline should adopt a range of self-learning, group learning, mentorship and reinforcement strategies that will over time, build the knowledge and confidence of nurses in implementing this guideline.
- Beyond skilled nurses, the infrastructure required to implement this guideline includes access to equipment and treatment materials. Orientation of the staff to the use of products and technologies must be provided and regular refresher training planned.

- Teamwork, collaborative assessment and treatment planning with the client and family and interdisciplinary team are beneficial in implementing guidelines successfully. Referral should be made as necessary to services or resources in the community or within the organization.

In addition to the strategies mentioned above, the RNAO has developed resources that are available at its website (www.rnao.org). A toolkit for implementing guidelines can be helpful, when used appropriately. A brief description of the toolkit can be found in Appendix M. A full version of the document in PDF format is also available at the RNAO website, www.rnao.org/bestpractices.

Process For Update / Review of Guideline

The Registered Nurses' Association of Ontario proposes to update this best practice guideline as follows:

1. Each nursing best practice guideline will be reviewed by a team of specialists (Review Team) in the topic area every three to five years following the last set of revisions.
2. During the period between development and revision, RNAO program staff will regularly monitor for new systematic reviews and randomized controlled trials and other relevant literature in the field.
3. Based on the results of the monitor, program staff will recommend an earlier revision period. Appropriate consultation with a team of members comprising original panel members and other specialists in the field will help inform the decision to review and revise the guidelines earlier than the targeted milestone.
4. Three months prior to the review milestone, the program staff will commence the planning of the review process by:
    a) Inviting specialists in the field to participate in the Review Team. The Review Team will be comprised of members from the original panel as well as other recommended specialists.
    b) Compiling feedback received, questions encountered during the dissemination phase as well as other comments and experiences of implementation sites.
    c) Compiling new clinical practice guidelines in the field, systematic reviews, meta-analysis papers, technical reviews, randomized controlled trial research, and conducting a comprehensive literature search based on the parameters of the original search.
    d) Developing detailed work plan with target dates and deliverables.
5. The revised guideline will undergo dissemination based on established structures and processes.

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Appendix A: Glossary of Terms

Actively Dying or Imminently Dying: A prognosis of death is expected to occur within hours to days.

Advance Care Planning: A process that involves understanding, reflection, communication and discussion between a patient and their family/health-care proxy for the purposes of prospectively identifying a surrogate, clarifying preferences and developing an individualized plan of care as the end of life nears. Advance care planning establishes a set of relationships, values and processes for approaching end-of-life decisions, and is specific to a patient's goals and values, age, culture and medical conditions. The focus of advance care planning is not merely death and the right to refuse treatment, but rather about living well and defining good care as a patient nears the end of life (Davison & Torgunrud, 2007).

Bereavement: "The entire experience of family members and friends in the anticipation, death, and subsequent adjustment to life surrounding the death of a loved one." (Christ, Bonnano, Malkinson, & Rubin, 2003, p. 554)

Best Interest: The substitute decision-maker who gives or refuses consent for treatment on behalf of an incapable person must take into consideration: the values and beliefs that the person knows the incapable person held when capable and believes he or she would still act on, if capable; any wishes expressed by the incapable person prior to becoming incapable with respect to treatment; whether the treatment is likely to improve, prevent deterioration or extent and rate of deterioration of the incapable person's condition or well-being; if treatment was not provided would the condition or well-being be likely to improve, remain the same or deteriorate; whether the expected benefits outweigh the risk of harm, and whether a less restrictive or less intrusive treatment be as beneficial as the proposed treatment (Health Care Consent Act, 1996, s.21).

Burnout: A biopsychosocial response to chronic emotional stress, which has three components: emotional exhaustion, depersonalization and a diminished sense of personal accomplishment (Erickson & Grove, 2008).

Capable: Has the corresponding meaning to capacity.

Capacity: A person is capable with respect to a treatment, admission to a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission or personal assistance service, and is able to appreciate the foreseeable consequences of a decision or lack of decision (Health Care Consent Act, 1996, s.4[1]).

- A person may be incapable with respect to some treatments and capable with respect to others.
- A person may be incapable with respect to a treatment at one time and capable at another time.
- If, after consent to a treatment is given or refused on a person's behalf in accordance with the Health Care Consent Act, the person becomes capable with respect to the treatment in the opinion of the health practitioner, the person's own decision to give or refuse consent to the treatment governs (Health Care Consent Act, 1996, c.2, Schedule A, s.15 & 16 [1])

Clinical Practice Guidelines/Best Practice Guidelines: Systematically developed statements to assist practitioner and client decisions about appropriate health care for specific clinical circumstances (Field & Lohr, 1990).

Complementary Therapies: An independent healing outside the realm of conventional medical practice and theory (Ferris et al., 2002). It focuses on the following: the whole person as a unique individual; the energy of the body and its influence on health and disease; the healing power of nature and the mobilization of the body's own resources to heal itself; and the treatment of underlying causes, rather than symptoms, of disease (MedicineNet, n.d.). Examples of complementary therapies include therapeutic touch massage, reiki, aromatherapy, music therapy or biofeedback.

Consensus: A process for making policy decisions. Consensus development makes the best use of available information, including scientific data and the collective wisdom of participants attempting to achieve consensus (Black et al., 1999).

Delirium: A mental disturbance that is sudden in onset and usually fluctuates, which is characterized by confusion, disordered speech and hallucinations.

Distributive Justice: The fair allocation of resources.

Dyspnea: A subjective symptom characterized by difficulty or laboured breathing, air hunger or shortness of breath.

Education Recommendations: Statements of educational requirements and educational approaches/strategies for the introduction, implementation and sustainability of the best practice guideline.

End of Life: There is no exact definition of end of life; however, evidence supports the following components: (1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death. Older age and frailty may be surrogates for life-threatening illness and comorbidity; however, there is insufficient evidence for understanding these variables as components of end of life.

Ethical Principles: Principles that serve to guide decision-making, which employ the doctrines of: beneficence (to do good); least harm (to do the least harm possible and to do harm to the fewest people); respect for autonomy (to allow people to make decisions that apply to their own lives); and justice (to be fair) (Rainbow, 2002).

Existential Distress: The experience of life with little or no meaning. It is defined as a state of powerlessness that arises from one's confrontation with one's own mortality and results in the consequent feelings of disappointment, futility and remorse that disrupt one's engagement with and purpose in life (Kissane, 2000).

Family: Those closest to the individual in knowledge, care and affection. Family may include: biological family; the family of acquisition (related by marriage/contract); and the family of choice and friends (including pets). Family is who the individual defines will be involved in his/her care and /or present at the bedside (Ferris et al., 2002).

Grief: The normal process of reacting to loss. The loss may be physical (e.g. death) social (e.g. divorce) or occupational (e.g. a job). Emotional reactions of grief can include anger, guilt anxiety, sadness and despair. Physical reactions of grief can include sleep disturbances, changes in appetite and physical problems or illness (MedicineNet, n.d.).

Health-care Practitioner: Health-care practitioners include:

- Audiologists and Speech-Language Pathologists;
- Chiropodists/ Podiatrist;
- Chiropractors;
- Dental Hygienists;
- Dental Surgeons;
- Denturists;
- Dieticians;
- Massage Therapists;
- Medical Laboratory Technologists
- Medical Radiation Technologists;
- Midwives;
- Nurses;
- Occupational Therapists;
- Optometrists;
- Physicians and Surgeons;
- Physiotherapists;
- Psychologists;
- Respiratory Therapists; or
- a naturopath registered as a drugless therapist under the Drugless Practitioners Act; or
- a category of persons prescribed by the regulations as health practitioners ("praticien de la santé").

Hospice Care: See "Hospice Palliative Care" definition. May also refer to care in a residential facility (i.e. a hospice).

Hospice Palliative Care: An approach to care that aims to "relieve suffering and improve the quality of living and dying. Such care approach strives to help patients and families: 1) Address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; and 2) prepare for and manage self-determined life closure and the dying process; and 3) cope with loss and grief during the illness and bereavement." (Ferris et al., 2002, p. 17)

Informed Consent: The following are elements required for consent to treatment: it must relate specifically to the treatment; it must be informed; it must be given voluntarily; and it must not be obtained through misrepresentation or fraud (Health Care Consent Act, 1996, s. 11[1]).

A consent to treatment is informed if, before giving it: The person received the information about the matters set out in subsection 3 of the Health Care Consent Act that a reasonable person in the same circumstances would require in order to make a decision about the treatment; and the person received responses to his or her requests for additional information about those matters (Health Care Consent Act, 1996, s. 11[2]). The matters referred to in subsection 2 are: the nature of the treatment; the expected benefits of the treatment; the material risks of the treatment; the material side effects of the treatment; alternative courses of action; and the likely consequences of not having the treatment (Health Care Consent Act, 1996, s. 11[3]).

Interprofessional: Teams representing different professions working together to reach a common goal and share a common decision-making process to enhance the achievement of this goal. The goal in health care is to work in a common effort with individuals and their families to enhance their goals and values. An interprofessional team typically includes one or more physicians, nurses, social workers, spiritual advisors, personal support workers and volunteers. Other disciplines may be part of the team, as resources permit and as appropriate (Ferris et al., 2002).

Interprofessional Education: Occasions when two or more professions learn with, from and about each other to improve collaboration and quality of care (D'Amour, Ferrada-Videla, Rodriguez, & Beaulieu, 2005).

Intractable or Refractory Symptoms: Symptom that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness (Palliative Care Network, n.d.)

Organization and Policy Recommendations: Statements of conditions required for a practice setting that enable the successful implementation of the best practice guideline. The conditions for success are largely the responsibility of the organization, although they may have implications for policy at a broader government or societal level.

Pain: A state of physical, emotional or mental lack of well-being or physical, emotional or mental uneasiness that ranges from mild discomfort or dull distress to acute, often unbearable, agony. Pain may be generalized or localized, and is the consequence of being injured or hurt physically or mentally, or of some derangement of or lack of equilibrium in physical or mental functions (as through disease), and that usually produces a reaction of wanting to avoid, escape or destroy the causative factor and its effects (Registered Nurses' Association of Ontario, 2007).

Palliative Care: Care that improves the quality of life of patients and their families facing life-threatening illness. Particular attention is paid to the prevention, assessment and treatment of pain and other symptoms, and to the provision of psychological, spiritual and emotional support. Palliative care is guided by the following principles:

- A focus on quality of life, which includes good symptom control.
- A whole person approach, which takes into account the person's past and current situation.
- Care that encompasses both the person with life-threatening illness and their family, friends and caregivers.
- A respect for the patient's autonomy and choices (e.g. place of care, treatment options).
- An emphasis on open and sensitive communication (AVERT: Averting HIV and AIDS, n.d).

Palliative Sedation: The intentional administration of sedative drugs in dosages and combinations required to reduce the consciousness of a terminal patient as much as necessary to adequately relieve one or more refractory symptoms (Palliative Care Network, n.d.).

Positive Affectivity: The extent to which a person feels enthusiastic and active.

Power of Attorney for Personal Care: A legal document that names a substitute decision-maker (called an attorney) and may contain directions about future health-care treatment and issues related to personal care. The document must be written and witnessed by two people. The individual writing the document must be 16 years of age and capable of making a power of attorney for personal care at the time of signature (Substitute Decision Act, 1992). Only an individual can create a power of attorney for him/herself: a substitute decision-maker cannot prepare a power of attorney on behalf of another person.

A person who gives or refuses consent to a treatment on an incapable person's behalf shall do so in accordance with the following principles:

1. If the person knows of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, the person shall give or refuse consent in accordance with the wish.
2. If the person does not know of a wish applicable to the circumstances that the incapable person expressed while capable and after attaining 16 years of age, or if it is impossible to comply with the wish, the person shall act in the incapable person's best interests (Health Care Consent Act, 1996, s. 21[1]).

Practice Recommendations: Statements of best practice directed toward the practice of health-care professionals that are ideally evidence based.

Quality of Life: The ability to enjoy normal life activities.

Randomized Controlled Trial: A clinical trial that involve at least one test treatment and one control treatment, concurrent enrollment and follow-up of the test- and control-treated groups, and in which the treatment(s) to be administered are selected by a random process.

Spirituality: An ultimate reality or transcendent dimension of the world; an inner path enabling a person to discover the essence of his or her being, or the deepest values and meanings by which people live (Kruse, Ruder, & Martin, 2007).

Stakeholder: An individual, group or organization with a vested interest in the decisions and actions of organizations, who may attempt to influence decisions and actions (Baker et al., 1999). Stakeholders include all individuals or groups who will be directly or indirectly affected by a change or solution to the problem.

Substitute Decision-maker: If a person is incapable of making a decision with respect to a treatment, consent may be given or refused on his /her behalf by another person. In order of hierarchy, the substitute decision-maker is: the incapable person's court-appointed guardian; attorney for personal care; a representative appointed by the Consent and Capacity Board; a spouse or partner; a child or parent; a parent of the incapable person who has only a right of access; a brother or sister; or any other relative (Health Care Consent Act, 1996, s. 20[1]). The provincial Public Guardian and Trustee is the substitute decision-maker of last resort if there is no other appropriate person to act for the incapable person (Government of Ontario, 1999).

A substitute decision-maker may give or refuse consent only if he or she (Health Care Consent Act, 1996, s. 20):

1. is capable of understanding the proposed treatment;
2. is at least 16 years old, unless he or she is the incapable person's parent;
3. is not prohibited legally from having access to the incapable person or giving or refusing consent on his or her behalf;
4. is available; and
5. is willing to assume the responsibility of giving or refusing consent.

A patient/resident cannot name a health-care practitioner, their health team or anyone else who provides them with health care as their attorney in a power of attorney for personal care, unless that person is a spouse, partner or relative (Substitute Decisions Act, 2992, s. 46[3]). The substitute decision-maker will cease to act on behalf of an incapable person if he/she should regain capacity.

Systematic Review: An application of a rigorous scientific approach to the preparation of a review article (National Health and Medical Research Centre, 1998). Systematic reviews establish where the effects of health care are consistent and research results can be applied across populations, settings and differences in treatment (e.g. dose), and where effects may vary significantly. The use of explicit, systematic methods in reviews limits bias (systematic errors) and reduces chance effects, thus providing more reliable results upon which to draw conclusions and make decisions (Higgins & Green, 2008).

Terminal Restlessness: See "Delirium."

Total Pain: A concept that describes pain from physical, psychological, social, emotional and spiritual perspectives. Under the "total pain" model, pain assessment in people who are dying requires multidimensional assessment that includes the patient's biomedical, psychological and psychiatric characteristics, as well as social, family, existential and spiritual influences.

Treatment Plan: In collaboration and agreement with the capable patient/resident (or with his/her substitute decision-maker in the event of incapacity), a treatment plan is developed by one or more health-care practitioners and addresses one or more of the person's health problems. Additionally, the plan may address health problems that the person is likely to have in the future, given their current health condition. The treatment plan also provides for the administration of various treatments and may also provide for the withholding or withdrawal of treatment in light of the person's current health condition (Health Care Consent Act, 1996 s.2:1).

Vigil: The practice of being present at the bedside for extended periods of time prior to death.

Appendix B: Guideline Development Process

The RNAO, with funding from the Government of Ontario, has embarked on a multi-year program of nursing best practice guideline development, implementation, evaluation, dissemination and support of uptake. One area of emphasis is nursing interventions related to care for adults in the last days and hours of their lives. This guideline was developed by a panel of nurses convened by the RNAO. This work was conducted independently of any bias or influence from the Government of Ontario.

In June 2009, a multidisciplinary panel with expertise in practice, education and research, from hospital, community and academic settings, was convened under the auspices of the RNAO. The panel discussed the purpose of their work, and achieved consensus on the scope of the best practice guideline. Subsequently, a literature search was conducted for clinical practice guidelines, systematic reviews, relevant research studies and other types of evidence. See Appendix C for details of the search strategy and outcomes.

Several international guidelines regarding end-of-life care were critically appraised and then chosen to inform the development of this guideline. Fifteen clinical practice guidelines were identified that met the following initial inclusion criteria:

- published in English;
- developed in 2000 or later;
- topic area was end-of-life care;
- any disease/illness;
- evidence based; and
- available for retrieval.

Members of the development panel critically appraised the 15 guidelines using the *Appraisal of Guidelines for Research and Evaluation Instrument* (AGREE Collaboration, 2001). This review resulted in the decision that four of the 15 guidelines were relevant to the scope of the current guideline, and would be used to inform the development process. These were:

1. Department of Health, National Health Service, United Kingdom. (2008). *End of life care strategy: Promoting high quality care for all adults at the end of life*. Retrieved June 15, 2011, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.

2. Health Canada. (2000). *A guide to end-of-life care for seniors*. Retrieved June 15, 2011, from http://dsp-psd.pwgsc.gc.ca/Collection/H88-3-31-2001-3E.pdf.

3. National Consensus Project for Quality Palliative Care. (2004). *Clinical practice guidelines for quality palliative care*. Retrieved June 15, 2011, from http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=5058.

4. Ontario Guidelines Advisory Committee. (2008). *Palliative care: Recognizing eligible patients and starting the discussion*. Retrieved June 15, 2011, from http://www.effectivepractice.org/site/ywd_effectivepractice/assets/pdf/2a_GAC_2A_-_PALL07_Improving_Care_Planning.pdf.

The panel members formed subgroups to undergo specific activities using the short-listed guidelines, evidence summaries, studies and other literature, for the purpose of drafting recommendations for nursing assessment and interventions. Community representatives were consulted for input and feedback. This process resulted in the development of practice, education, and organization and policy recommendations. The panel members as a whole reviewed the first draft of recommendations, discussed gaps, reviewed the evidence and achieved consensus on a final set of recommendations.

The completed draft was submitted to a set of external stakeholders for review and feedback; acknowledgement of these stakeholders is provided at the beginning of this document. Stakeholders represented various health-care professional groups, clients and family members, and professional associations. External stakeholders were provided with specific questions for comment, as well as the opportunity to provide general feedback and impressions.

The feedback from stakeholders was compiled and reviewed by the development panel. Discussion and consensus resulted in revisions to the draft document prior to publication.

Appendix C: Process for Systematic Review/ Search Strategy

The search strategy utilized during the development of this guideline focused on two key areas. The first was the identification of clinical practice guidelines published on the topic of end-of-life care, while the second was a literature review to identify theoretical literature, primary studies, meta-analyses and systematic reviews published in this area between 2003 and 2009.

STEP 1.Database Search

A database search for existing evidence related to end-of-life care was conducted by a health sciences librarian using search terms generated by the development panel. The search strategy utilized by the Cochrane Effective Practice and Organization of Care group was used to formulate the final search strategy. An initial search of the Cochrane Database of Systematic Reviews, MEDLINE, ProQuest, CINAHL, WebScience, PsychInfo, Embase and Ageline databases for guidelines, primary studies, theoretical literature and systematic reviews published between 2003 and 2009 was conducted using the following search terms: *"Death/dying," "Terminal care," "End of life care," "Palliative care," "Hospice care," "Grief/ bereavement and death/end of life/ last hours and days of life," "Setting of care and death/end of life/ last hours and days of life," "Traumatic death and death/end of life/ last hours and days of life," "Caregiver support and death/end of life/ last hours and days of life, "Chronic illness and end of life care/ last hours and days of life, "Life limiting illness/ life threatening," "Traumatic death," "Withdrawal and withholding of interventions," "Last days of living," "Terminal sedation," "Communication and death/ end of life/ last hours and days of life," "Culture and death," "Comfort care and end of life/ last hours and days of life," "Do not resuscitate," "Spirituality and end of life care," "Loss and death/end of life/ last hours and days of life," "Hope and death/end of life/ last hours and days of life," "Dignity and death/end of life/ last hours and days of life, "Good death," "Pronouncement," "Decision making and death/ end of life/ last hours and days of life," "Advance care planning and death/end of life/ last hours and days of life, "Education and end of life care," "Interprofessional care" and "End of life care".*

This search was structured to answer the following questions:

1. What knowledge and skills do nurses require to identify, assess, intervene and evaluate individuals and their families during the last days and hours of life?
2. What knowledge, skills and tools do nurses require to support individuals and their families in making informed choices during the last hours and days of life?

3. What palliative interventions are needed to address the experiences faced by individuals and their families during the last days and hours of life?

4. What supports are needed to assist nurses to providing high quality care in the last hours and days of life?

As directed by the panel, additional literature searches were conducted to supplement the results of the systematic review report.

STEP 2.Structured Website Search

One individual searched an established list of websites for content related to the topic area in March 2009. This list of websites was compiled based on existing knowledge of evidence-based practice websites, known guideline developers and recommendations from the literature. The presence or absence of guidelines was noted for each site searched, as well as the date searched. Some websites did not house guidelines, but directed readers to another website or source for guideline retrieval. Guidelines were downloaded if full versions were available online, or were ordered by telephone or email if they were not available online.

- Abstract for Cochrane Reviews: www.cochrane.org/reviews
- Alberta Heritage Foundation for Medical Research: www.ahfmr.ab.ca/publications
- Agency for Healthcare Research and Quality: www.ahrq.gov
- Alberta Medical Association Clinical Practice Guidelines: www.albertadoctors.org
- American Academy of Hospice and Palliative Medicine: www.aahpm.org
- American Nephrology Nurses' Association: www.annanurse.org
- Annals of Internal Medicine: www.annals.org
- Australian Centre of Grief and Bereavement: www.grief.org.au/welcome.html
- Bandolier Journals: www.medicine.ox.ac.uk/bandolier
- British Columbia Office of Health Technology Assessment: www.chspr.ubc.ca
- British Columbia Council on Clinical Practice Guideline: www.bcguidelines.ca/gpac
- Canadian Coordinating Office for Health Technology Assessment: www.ccohta.ca
- Canadian Health Network: www.canadian-health-network.ca
- Canadian Hospice Palliative Care Organization: www.chpca.net
- Canadian Institute for Health Information: www.cihi.ca
- CMA Infobase; Clinical Practice Guideline: http://mdm.ca/cpgsnew/cpgs/index.asp
- Commission on the Future of Health Care in Canada: http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/romanow-eng.php
- CRESTNI Health- www.crestni.org.uk
- Database of Abstracts of Reviews of Effectiveness: www.crd.york.ac.uk/crdweb
- Dying Well: www.dyingwell.org
- Evidence-based on Call: www.eboncall.org
- EndLink: http://endoflife.northwestern.edu/index.cfm
- European Observatory on Health Care for Chronic Conditions, World Health Organization: www.who.int/chronic_conditions/en/
- Guideline Advisory Committee: www.gacguidelines.ca
- Guideline International Network: www.g-i-n.net
- Health Canada: www.hc-sc.gc.ca
- Health Evidence: http://health-evidence.ca
- Hospice Foundation of America: www.hospicefoundation.org
- Institute for Clinical Evaluative Sciences: www.ices.on.ca
- Institute for Clinical Systems Improvement: www.icsi.org
- Joanna Briggs Institute: www.joannabriggs.edu.au

- Medic8.com: www.medic8.com/ClinicalGuidelines.htm
- Monash University Centre for Clinical Effectiveness: www.monash.edu.au/healthservice/cce/evidence
- National Guideline Clearing House: www.guidelines.gov
- National Institute for Clinical Excellence: www.nice.org.uk
- National Palliative Care Research Center: www.npcrc.org
- New Zealand Guidelines Group: www.nzgg.org
- NHS Centre for Reviews and Dissemination: www.york.ac.uk/inst/crd
- National Institutes of Health Consensus Development Program: http://consensus.nih.gov
- NIHR Health Technology Assessment Programme: www.ncchta.org
- PEDro: The Physiotherapy Evidence Database: www.pedro.org.au
- Royal College of General Practitioners: www.rcgp.org.uk
- Royal College of Nursing: www.rcn.org.uk/index.php
- Royal College of Physicians: www.rcplondon.ac.uk
- Scottish Intercollegiate Guidelines Network: www.sign.ac.uk
- Social Work in Hospice and Palliative Care Network-- http://swhpn.org/lhp/library.html
- SUMSearch: http://sumsearch.uthscsa.edu
- The Qualitative Report: www.nova.edu/ssss/QR
- TRIP Database: www.tripdatabase.com
- Virginia Henderson International Nursing Library: www.nursinglibrary.org

Step 3. Search Engine Web Search

In addition, a website search for existing practice guidelines related to end-of-life care was conducted via the search engine Google (www.google.com), using key search terms. One individual conducted this search, and noted the results of the search, the websites reviewed and dates accessed. A summary of the search results was then written.

Step 4. Hand Search/ Panel Contribution

The following key journals were hand-searched over a 12-month period, up to May 2010:

- *Palliative and Supportive Care*
- *Palliative Medicine*
- *Supportive Care in Cancer*
- *European Journal of Palliative Care*
- *Hospice and Palliative Nursing*
- *International Journal of Palliative Nursing*
- *Journal of Pain and Symptom Management*
- *Journal of Palliative Care*

Panel members were also asked to review their personal archives to identify guidelines not previously found via the search strategies noted above. Two guidelines were identified, but after careful review were deemed to be outside the scope of the guideline, and were therefore not included in the review.

Search Results

The search strategy described above resulted in the retrieval of 6,571 abstracts on the topic of end-of-life care. These abstracts were then independently screened by two research assistants to identify duplications, and assess for inclusion and exclusion criteria established by the panel.

In addition, 14 clinical practice guidelines were identified that met the screening criteria (Appendix B) and were critically appraised using the AGREE Instrument (AGREE Collaboration, 2001):

1. Caritas Health Group; Palliative Care Clinical Practice Guideline Committee. (2006). *Palliative sedation*. Retrieved June 15, 2011, from http://K\DATA\RPCProgramBinder\Section3Clinical\3AGuidelines\3A6PalliativeSedation.doc.
2. Department of Health, National Health Service, United Kingdom. (2008). *End of life care strategy: Promoting high quality care for all adults at the end of life*. Retrieved June 15, 2011, from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.
3. Health Canada. (2000). *A guide to end of life care for seniors*. Retrieved June 15, 2011, from http://dsp-psd.pwgsc.gc.ca/Collection/H88-3-31-2001-3E.pdf.
4. Ian Anderson Continuing Education Program, University of Toronto. (2005). *End of life decision making*. Retrieved June 16, 2011, from www.cme.utoronto.ca/endoflife/End-of-Life%20Decision-Making.pdf
5. Institute for Clinical System Improvement. (2009). Palliative care (guideline). Retrieved June 16, 2011, from www.icsi.org/home/palliative_care_11918.html.
6. Institute for Clinical Systems Improvement. (2008). *Health care guideline: Palliative care*, 2nd edn. Retrieved June 15, 2011, from www.icsi.org/guidelines_and_more/gl_os_prot/other_health_care_conditions/palliative_care/palliative_care_11875.html.
7. Missouri Department of Health and Senior Services & Missouri End of Life Coalition's End of Life in the Nursing Home Task Force. (2003). *Guidelines for end of life care in long-term care facilities*. Retrieved June 17, 2011, from http://health.mo.gov/safety/showmelongtermcare/pdf/EndofLifeManual.pdf.
8. National Comprehensive Cancer Network. (2003). *Advanced cancer and palliative care: Treatment guidelines for patients*. Retrieved June 15, 2011, from www.cancer.org/downloads/CRI/F9643.00.pdf.
9. National Consensus Project for Quality Palliative Care. (2004). *Clinical practice guidelines for quality palliative care*. Retrieved June 15, 2010, from http://www.guideline.gov/summary/summary.aspx?ss=15&doc_id=5058.
10. National Institute for Clinical Excellence (2004). *Improving Supportive and Palliative Care for Adults with Cancer*. [Online] http://www.nice.org.uk/nicemedia/pdf/csgspmanual.pdf
11. Ngo-Metzger, Q., August, K., Srinivasan, M., Liao, S., & Meyskens, F. (2008). *End of life care: Guideline for patient-centered communication*. American Family Physician, 77, 167–174.
12. NSW Department of Health (2005). *Guideline for end of life care and decision-making*. Retrieved June 16, 2011, from http://www.cena.org.au/nsw/end_of_life_guidelines.pdf.
13. Ontario Guidelines Advisory Committee. (2008). *Palliative care: Recognizing eligible patients and starting the discussion*. Retrieved June 15, 2011, from http://www.effectivepractice.org/site/ywd_effectivepractice/assets/pdf/2a_GAC_2A_-_PALL07_Improving_Care_Planning.pdf.
14. Qaseem, A., Snow, V., Casey, D., Cross, T. and Owens, D. (2008). *Evidence-based interventions to improve the palliative care of pain, dyspnea, and depression at the end of life: A clinical practice guideline from the American College of Physicians*. Annals of Internal Medicine, 148(2), 141-146.

Appendix D: Tools for Estimating Length of Survival for Individuals at the End of Life

Palliative Performance Scale (PPS), Version 2

Instructions for Using the PPS

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient, which is then assigned as the PPS% score.
2. Begin at the left column and read downward until the appropriate ambulation level is reached; then read across to the next column and downward again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, "leftward" columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others. *Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances, but who is otherwise fully conscious with good intake would be scored at PPS 50%.*
3. PPS scores are in 10% increments only. Sometimes, several columns are easily placed at one level, but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a "half-fit" value of PPS 45%, for example, is not correct. The combination of clinical judgment and "leftward precedence" is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

PPS level	Ambulation	Activity & evidence of disease	Self-care	Intake	Conscious level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable normal job/work Significant disease	Occasional assistance necessary	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Considerable assistance required	Normal or reduced	Full or confusion
50%	Mainly sit/lie	Unable to do any work Extensive disease	Mainly assistance	Normal or reduced	Full or confusion
40%	Mainly sit/lie	Unable to do most activity Extensive disease	Total care	Normal or reduced	Full or drowsy ± confusion
30%	Totally bedbound	Unable to do any activity Extensive disease	Total care	Normal or reduced	Full or drowsy ± confusion
20%	Totally bedbound	Unable to do any activity Extensive disease	Total care	Minimal to sips	Full or drowsy ± confusion
10%	Totally bedbound	Unable to do any activity Extensive disease	Total care	Mouth care only	Drowsy or coma ± confusion
0%	Death	–	–	–	–

© Victoria Hospice Society, BC, Canada (2001), www.victoriahospice.org.

For more information about this tool, please visit www.victoriahospice.org/sites/default/files/pps_english.pdf

Palliative Prognostic Index (PPI)

The PPI relies on the assessment of performance status using the Palliative Performance Scale (PPS, oral intake, and the presence or absence of dyspnea, edema, and delirium).

Performance status/Symptoms	Partial score
Palliative Performance Scale	
10–20	4
30–50	2.5
>60	0
Oral Intake	
Mouthfuls or less	2.5
Reduced but more than mouthfuls	1
Normal	0
Edema	
Present	1
Absent	0
Dyspnea at rest	
Present	3.5
Absent	0
Delirium	
Present	4
Absent	0

Scoring

PPI score > 6 = survival shorter than 3 weeks

PPI score >4 = survival shorter than 6 weeks

PPI score ≤4 = survival more than 6weeks

Reprinted from Journal of Pain and Symptom Management, Vol. 35, No. 6, Stone, C., Tierman, E., & Dooley, B., Prospective Validation of the Palliative Prognostic Index in Patients with Cancer, 617–622, Copyright (2008), with permission from Elsevier.

Palliative Prognostic Score (PaP)

The PaP uses the Karnofsky Performance Score (KPS) and five other criteria to generate a numerical score from 0 to 17.5 to predict 30 day survival (higher scores predict shorter survival).

Performance status/Symptoms	Partial score
Dyspnea	
No	0
Yes	1
Anorexia	
No	0
Yes	1
KPS	
≥50	0
30–40	0
10–20	2.5
Clinical Prediction of Survival (weeks)	
>12	0
11–12	2.0
9–10	2.5
7–8	2.5
5–6	4.5
3–4	6.0
1–2	8.5

Performance status/Symptoms	Partial score
Total WBC	
Normal (4,800–8,500 cell/mm3)	0
High (8,501–11,000 cell/mm3)	0.5
Very high(>11,000 cell/mm3)	1.5
Lymphocyte percentage	
Normal (20.0–40.0%)	0
Low (12.0–19.9%)	1.0
Very low (0–11.9%)	2.5
Risk groups	Total score
A. 30-day survival probability >70%	0–5.5
B. 30-day survival probability 30–70%	5.6–11.0
C. 30-day survival probability <30%	11.1–17.5

PaP score = Dyspnea score + Anorexia score + KPS score + CPS score + Total WBC score + Lymphocyte percentage score.

Reprinted from Journal of Pain and Symptom Management, Vol. 17, No. 4, Maltoni, M, Nanni, O., Pirovano, M., Scarpi, E., Indelli, M., Martini, C., et al., Successful Validation of the Palliative Prognostic Score in Terminally Ill Cancer Patient, 240–247., Copyright (1999), with permission from Elsevier.

Appendix E: Clinical Indicators of Decline

Diseases such as chronic obstructive pulmonary disease or congestive heart failure run a more fluctuating course and result in death in a less predictable timeframe than diseases such as renal disease or dementia. Each exacerbation can lead to remission (and future exacerbation) or death; knowing which will occur on any given admission is extremely challenging.

General indicators of poorer prognosis (life expectancy of only weeks to many weeks) include poor performance status, impaired nutritional status and a low albumin level.

Disease	Specific indicators
Chronic obstructive pulmonary disease[1,2]	Less than 6 months of life expected: • Disabling dyspnea at rest, unresponsive to bronchodilators, resulting in decreased functional activity, bed to chair existence, often exacerbated by other debilitating symptoms such as fatigue and cough. • FEV1 after bronchodilators <30%. • Increased visits to emergency department/hospital for pulmonary infections and/or respiratory failure. • Pulmonary hypertension with cor pulmonale/right heart failure. • 24-hour home oxygen with pO2 <50 mmHg and/or pCO2 > 50mmHg and documented evidence of cor pulmonale. • Oxygen saturation <88% with supplementary oxygen. • Unintentional weight loss >10% over preceding 6 months. • Resting tachycardia >100/min.
Congestive heart failure[3]	< 6 month of life expected: • Chest pain, dyspnea at rest or minimal exertion and already optimally treated with diuretics and vasodilators. • Congestive heart failure >2 hospitalizations in the year. • 50% increase in dose of oral medication or adding new class of drug. • Left ventricular ejection fraction <20%. • Creatinine >350 µmol/L.
	Only a few weeks remaining: • History of cardiac arrest and resuscitation. • History of unexplained syncope. • Resistant dysrhythmias. • Hypertension. • Insulin-dependent diabetes. • Nicotine use. • Prior coronary artery bypass.

[1]Minnesota Hospice Organization. National hospice organization medical guidelines for determining prognosis in selected non-cancer diseases: a physician's guideline. St. Paul: Hospice Minnetsota; 1996.

[2]Pfeifer, M. End of life decision making: special considerations in the COPD patient. Medscape G Med. 1999; 1(3). Available from: www.medscape.com/viewarticle/408735

[3]Derfler, M., Jacob, M., Wolf, RE., Bleyer, F. & Hauetman, PJ. Mode of death from congestive heart failure: implications for clinical management. Am J Geriatr Cardiol. 2004; 13(6): 299-304.

Disease	Specific indicators
Dementia[2,4,5]	Month to several months of life expected (all predictors should be present): • Mini-Mental State Examination <12. • Unable to ambulate without assistance. • Unable to dress without assistance. • Unable to bathe without assistance. • Urinary and fecal incontinence. • Unable to speak or communicate meaningfully. • Unable to swallow. • Increasing frequency of medical complications (e.g. aspiration pneumonia, urinary tract infections, decubitus ulcers).
Renal disease	Weeks to several month of life expected: • Creatinine clearance < 10cc/min (<15cc/min for diabetics. • Serum creatinine > 700 µmol/L (>530 µmol/L for diabetics) • Confusion and/or obtundation (less than full mental capacity) • Intractable nausea and vomiting • Generalized pruritus • Restlessness • Oliguria (urine output <40cc/24 hr) • Intractable hyperkalemia (>7 mmol/L) • Intractable fluid overload
Stroke[2]	Days to weeks of life expected: • During the acute phase any of the following: ▪ Coma beyond three days duration and dense paralysis ▪ Comatose patients with any four of the following on day 3: • Abnormal brain stem response • Absent verbal response • Absent withdrawal response to pain • Serum creatinine >130 µmol/L • Age >70 • Imaging findings such as: • Large hemorrhage, with ventricular extension • Midline shift >1.5 cm or bihemisphere infarcts, cortical and subcortical infarcts • Basilar artery occlusion

Source: Pereira, J. L., Associates. *Pallium palliative pocketbook: A peer-reviewed, referenced resource*. 1st Cdn, Canada: The Pallium Project; 2008. Reprinted by permission of The Pallium Project

[4]Sachs, GA, Shega, JW, Cox-Hayley, D. Barriers to excellent end-of-life care for patients with dementia. J Gen Intern Med. 2004; 19: 1057-63.

[5]Allen, RS., Kwak, J., Lokken, KL., Haley, W. End of life issues in the context of Alzheimer's Disease. Alz Care Quart. 2003; 4(4): 312-30.

Appendix F: Edmonton Symptom Assessment System (revised version)

Please circle the number that best describes how you feel NOW:

No pain	1	2	3	4	5	6	7	8	9	10	Worst possible pain
No tiredness *Tiredness = lack of energy*	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
No drowsiness *Drowsiness = feeling sleepy*	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
No nausea	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
No lack of appetite	1	2	3	4	5	6	7	8	9	10	Worst possible lack of appetite
No shortness of breath	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
No depression *Depression = feeling sad*	1	2	3	4	5	6	7	8	9	10	Worst possible depression
No anxiety *Anxiety = feeling nervous*	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Best wellbeing *Wellbeing = how you feel overall*	1	2	3	4	5	6	7	8	9	10	Worst possible wellbeing
No _____ Other problem (e.g. constipation)	1	2	3	4	5	6	7	8	9	10	Worst possible _____

Patient's name: _____

_____

Date: _____

Time: _____

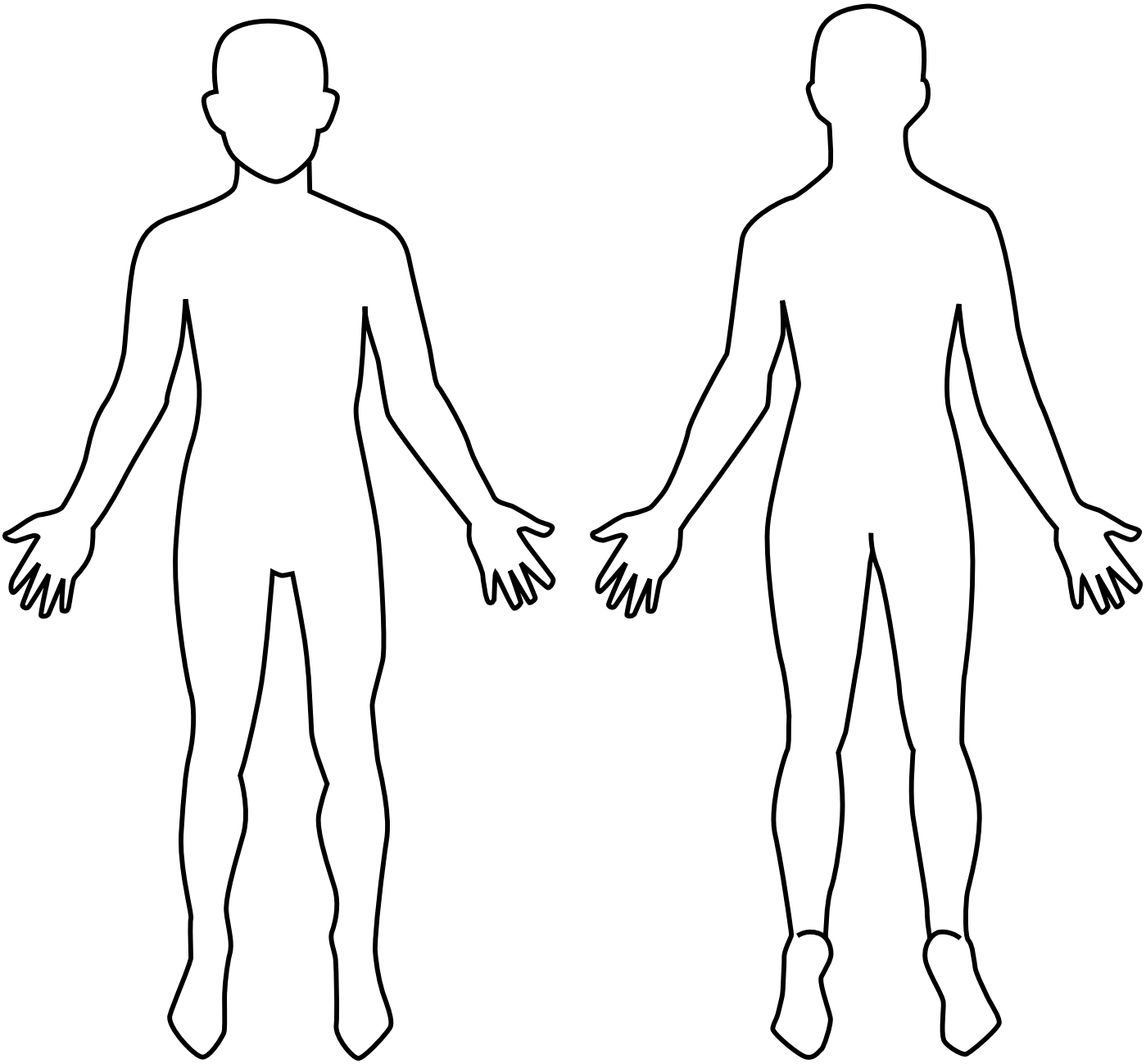
Completed by (check one):

- ☐ Patient
- ☐ Family caregiver
- ☐ Health-care professional caregiver
- ☐ Caregiver-assisted

Reprinted from Journal of Pain and Symptom Management, Vol. 41, No. 2, Watanabe, S. M., Nekolaichuk, C., Beaumont, C., Johnson, L., Myers J., & Strasser, F., A Multi-Centre Comparison of Two Numerical Versions of the Edmonton Symptom Assessment System in Palliative Care Patients, 456-468, Copyright (2011), with permission from Elsevier.

For more information about this tool, please visit: www.palliative.org/PC/ClinicalInfo/AssessmentTools/ESAS%20ToolsIdx.html.

Please mark on these pictures where it is you hurt.



Appendix G: Frommelt Attitude Toward Care of the Dying Scale

This scale's purpose is to determine how nurses feel about certain situations in which they are involved with patients. All statements concern nursing care given to the dying person and/or his/her family. Where there is reference to a dying patient, assume it refers to a person who is considered to be terminally ill, with six months or fewer to live.

Please circle the letter following each statement that corresponds, to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale.

Positive items are scored one (strongly disagree) to five (strongly agree). Scores are reversed for negative items. Possible scores can range from 30–150. A higher score indicates a more positive attitude toward caring for this patient population.

SD = Strongly Disagree D = Disagree U = Uncertain A = Agree SA = Strongly Agree

1. Giving nursing care to the dying person is a worthwhile learning experience.	SD	D	U	A	SA
2. Death is not the worst thing that can happen to a person.	SD	D	U	A	SA
3. I would be uncomfortable talking about impending death with the dying person.	SD	D	U	A	SA
4. Nursing care for the patient's family should continue throughout the period of grief and bereavement.	SD	D	U	A	SA
5. I would not want to be assigned to care for a dying person.	SD	D	U	A	SA
6. The nurse should not be the one to talk about death with the dying person.	SD	D	U	A	SA
7. The length of time required to give nursing care to a dying person would frustrate me.	SD	D	U	A	SA
8. I would be upset when the dying person I was caring for gave up hope of getting better.	SD	D	U	A	SA
9. It is difficult to form a close relationship with the family of a dying person.	SD	D	U	A	SA
10. There are times when death is welcomed by the dying person.	SD	D	U	A	SA
11. When a patient asks, "Nurse am I dying?", I think it is best to change the subject to something cheerful.	SD	D	U	A	SA
12. The family should be involved in the physical care of the dying person.	SD	D	U	A	SA
13. I would hope the person I'm caring for dies when I am not present.	SD	D	U	A	SA
14. I am afraid to become friends with a dying person.	SD	D	U	A	SA
15. I would feel like running away when the person actually died.	SD	D	U	A	SA
16. Families need emotional support to accept the behavior changes of the dying person.	SD	D	U	A	SA
17. As a patient nears death, the nurse should withdraw from his/her involvement with the patient.	SD	D	U	A	SA
18. Families should be concerned about helping their dying member make the best of his/her remaining life.	SD	D	U	A	SA

19. The dying person should not be allowed to make decisions about his/her physical care.	SD	D	U	A	SA
20. Families should maintain as normal an environment as possible for their dying member.	SD	D	U	A	SA
21. It is beneficial for the dying person to verbalize his/her feelings.	SD	D	U	A	SA
22. Nursing care should extend to the family of the dying person.	SD	D	U	A	SA
23. Nurses should permit dying persons to have flexible visiting schedules.	SD	D	U	A	SA
24. The dying person and his/her family should be the in-charge decision-makers.	SD	D	U	A	SA
25. Addiction to pain relieving medication should not be a nursing concern when dealing with a dying person.	SD	D	U	A	SA
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	SD	D	U	A	SA
27. Dying persons should be given honest answers about their condition.	SD	D	U	A	SA
28. Educating families about death and dying is not a nursing responsibility.	SD	D	U	A	SA
29. Family members who stay close to a dying person often interfere with the professionals job with the patient.	SD	D	U	A	SA
30. It is possible for nurses to help patients prepare for death.	SD	D	U	A	SA

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Appendix H: Tips for Conducting a Family Conference

After the Pre-conference, proceeds either to 2 **or 3.

1. Pre-conference:

a. Clarify conference goals and roles with the health-care team.
b. Identify participants (health-care team, individual and family).
c. Organize date, time and location (private space when available).

2. Conference with individual capable to make decisions and family if desired:

a. Introduce self and others.
b. Review meeting goals; clarify if specific decisions need to be made.
c. Determine urgency of decision-making.
- Establish ground rules: Each person will have an opportunity to ask questions and express views without interruption; a legal decision-maker will be identified; and the importance of supportive decision-making will be described.

d. Review health status:
i. Determine what the patient and their family already know: "Tell us what you understand about your current situation."
ii. Review current health status.

iii. Ask individual and family members if they have any questions about the current situation.

e. Clarify expectations

f. Clarify beliefs and values to determine what goals are most important to avoid or achieve.

g. Discuss practical implications of preferences and expectations (i.e. are goals realistic and achievable?).

h. Allow time for private discussion.

i. Review and/or set goals of care.

3. Conference with substitute decision-maker(s) and others as identified:

a. Introduce self and others.

b. Clarify role of substitute decision-maker(s) and confirm willingness to participate in decision-making.

c. Review meeting goals; clarify if specific decisions need to be made.

d. Determine the urgency of decision-making.

e. Establish ground rules: Each person will have an opportunity to ask questions and express views without interruption; a legal decision-maker will be identified; and the importance of supportive decision-making will be described.

f. Review health status.

i. Determine what the substitute decision-maker(s)/family already know: "Tell us what you understand about the individual's current situation."

ii. Review current health status.

iii. Ask the substitute decision-maker(s) and family members if they have any questions about the current situation.

g. Clarify expectations:

i. Ask substitute decision-maker(s): "What do you believe the individual would choose if he/she could speak for him or herself?"

ii. Based on what the substitute decision-maker(s) understand about what the individual would have wanted, ask he/she: "What do you think should be done?"

h. Clarify beliefs and values to determine what goals are most important to avoid or achieve.

i. Discuss practical implications of preferences and expectations (i.e. are goals realistic and achievable?).

j. Allow time for private discussion.

k. Review and/or set goals of care.

4. Wrap-up:

a. Summarize consensus, disagreements, decisions and goals of care.

b. Caution against unexpected outcomes.

c. Identify family spokesperson for ongoing communication.

d. Document in the health care record: who was present, goals of care, what decisions were made, follow-up plan.

e. Maintain contact with individual, substitute decision-maker(s), family and health-care team.

f. Schedule follow-up meetings as needed.

N.B. When there is no consensus:

- Determine unmet needs for information and support.
- Assist the individual/substitute decision-maker(s) to access resources to address unmet needs.
- Reinforce role of substitute decision-maker if applicable.
- Schedule a follow-up conference.

Adapted from Ambuel B and Weissman DE. Moderating an end-of-life family conference, 2nd Edition. Fast Facts and Concepts. August 2005; 16. Available at: http://www.eperc.mcw.edu/fastfact/ff_016.htm

Appendix I: Canadian Hospice Palliative Care Association Square of Care

Square of Care			History of issues, opportunities, associated expectations, needs, hopes, fears Examination- assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity, Goals of care, Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death, Issue prioritization, Therapeutic priorities, options Treatment choices, consent, Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/develop plan of care- address issues/opportunities. Delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies.	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Confirmation Understanding Satisfaction Complexity Stress Concerns, issues, questions
			Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation
			PROCESS OF PROVIDING CARE					
Primary diagnosis, prognosis, evidence Secondary diagnoses- dementia, substance use, trauma Co-morbidities- delirium, seizures Adverse events- side effects, toxicity Allergies	Disease Management	COMMON ISSUES	Patient/Family					
Pain, other symptoms Cognition, level of consciousness Function, safety, aids, Fluids, nutrition Wounds, Habits- alcohol, smoking	Physical							
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self-image, self esteem	Psychological							
Cultural values, belief, practices Relationship, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	Social							
Meaning, value Existential, Transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual							
Activities of daily living Dependents, pets Telephone access, transportation	Practical							
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals, Death pronouncement, certification, Perideath care of family, handling or body Funerals, memorial	End of life/ Death management							
Loss, Grief- acute, chronic, anticipatory Bereavement planning, Mourning	Loss, Grief							

Ferris, FD., Balfour, HM., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. West, P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002.

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APPENDICIES

Appendix J: Strategies for Help Individuals Engage in Decision-making at the End of Life

Patient Engagement in Decision-making

Nurse/patient relationship	Sharing of power and control	Communication and assessment
Promote discussion if families are struggling with conflict (Hsieh, Shannon, & Curtis 2006).	Emphasize the need to consider what information was essential for patients and relatives, use concrete examples and lay language, and provide time for decision-making (Hanna-Mari & Marja-Liisa, 2006).	Offer emotional and existential support through discussion, listening, being present and attending to patients and relatives (Hanna-Mari & Marja-Liisa, 2006).
Raise issues related to end-of-life care early in the course of a life-threatening illness (Thelen, 2005).	Provide resources on how to access reliable trustworthy information (National Advisory Committee: *A Guide to End-of-life Care for Seniors, 2000*).	Evaluate patients/ and their relatives' competence for decision-making and support them in accepting the medical facts (Hanna-Mari & Marja-Liisa, 2006).
Approach the topic sensitively (National Advisory Committee: *A Guide to End-of-life Care for Seniors, 2000*).	Be aware of influence providers have in influencing decisions by critically analyzing /reflecting on extent to which they have control over patient/ situation (Hilden & Honlasalo, 2006).	Clarify patients' and relatives' views (Hanna-Mari & Marja-Liisa, 2006).
Be available to listen to concerns and provide uninterrupted time (National Advisory Committee: *A Guide to End-of-life Care for Seniors, 2000).*	Reframe decisions regarding withholding sustaining treatment as allowing the disease to take its course rather than "not continuing treatments that merely prolong suffering." (Lyness, 2004)	Patient's and their family's need to understand their overall medical condition to plan effectively and how their illness and various treatment options will affect them within the context of their daily lives (Davison & Torgunrud, 2007).
Recognize that each person has unique tolerance for discomfort and a unique drive to live (Loomis, 2009).	Recognized that people may choose to endure physical or emotional distress as part of their spiritual journey (Loomis, 2009).	Facilitate frank assessment of the likelihood of whether withholding or stopping sustaining treatment will be beneficial (Lyness, 2004).

Patient Engagement in Decision-making in the Manner they Prefer

Nurse/patient relationship	Sharing of power and control	Communication and assessment
Encourage family members to spend time at the bedside and talk with them about their perceptions	Identify potential conflicts in advance care planning and effectively manage conflicts	Offer clear, thorough information, rather than requiring family members to ask (Meeker & Jezewski, 2005).
Review the patient's preferences on a regular basis and update documentation – Patient should be reminded that advance directives can be revised at any time (Davison & Torgunrud, 2007; Kass-Bartelmes & Hughes, 2004)	Allow family members time to arrive at consensual decisions (Meeker & Jezewski, 2005).	Assess for conflict within family (Meeker & Jezewski, 2005).
Look at the patient through both their own eyes and the eyes of the patients and family members (Mazanec & Tyler, 2003).	Facilitate the process of substitute decision-making (Meeker & Jezewski, 2005).	Frequently explain and update patient and their substitute decision-maker about the patients' current health status (Gillick, 2006)
Apply the patient's desires to actual circumstances (Davison & Torgunrud, 2007)	Helping achieve consensus among family members and act as an arbitrator between family members (Thelen, 2005).	Engage the patient in prioritizing their goals of care (Gillick, 2006).
Treat the family with compassion and respect (Thelen, 2005)	Conversations about difficult issues may be started by asking the patient open-ended questions and listening attentively to their responses (Griffie, Nelson-Marten, & Muchka, 2004)	Initiate a guided discussion which involves sharing medical knowledge and treatments applicable to a patient's particular situation and find out the patients' preferences for providing or withholding treatments under certain scenario's (Davison & Torgunrud, 2007)

Appendix K: Canadian Hospice Palliative Care Association Square of Care and Organization

Square of Care and Organization

	History of issues, opportunities, associated expectations, needs, hopes, fears Examination- assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity, Goals of care, Requests for withholding/withdrawing, therapy with no potential for benefit, hastened death, Issue prioritization, Therapeutic priorities, options Treatment choices, consent, Surrogate decision-making Advance directives Conflict resolution
	Assessment	Information-sharing	Decision-making
	PROCESS OF PROVIDING CARE		

Primary diagnosis, prognosis, evidence Secondary diagnoses- dementia, substance use, trauma Co-morbidities- delirium, seizures Adverse events- side effects, toxicity Allergies	Disease Management	COMMON ISSUES
Pain, other symptoms Cognition, level of consciousness Function, safety, aids, Fluids, nutrition Wounds, Habits- alcohol, smoking	Physical	
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self-image, self esteem	Psychological	
Cultural values, belief, practices Relationship, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	Social	
Meaning, value Existential, Transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual	
Activities of daily living Dependents, pets Telephone access, transportation	Practical	
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals, Death pronouncement, certification, Perideath care of family, handling or body Funerals, memorial	End of life/ Death management	
Loss, Grief- acute, chronic, anticipatory Bereavement planning, Mourning	Loss, Grief	

Patient /

RESOURCES		
Financial	Human	Informational
Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records- health, financial, human resource, assets Resource materials, eg. books, journals, internet, internet resource directory

APPENDICIES

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Care Planning	Care Delivery	Confirmation
Setting of care Process to negotiate/develop plan of care- address issues/ opportunities. Delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies.	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Confirmation Understanding Satisfaction Complexity Stress Concerns, issues, questions

PROCESS OF PROVIDING CARE

/ Family

FUNCTIONS	
Governance & Administration	Leadership- board, management Organizational structure, accountability
Planning	Strategic planning Business planning Business development
Operations	Standards of practice, policies & procedures, data collection/documentation, guidelines Resource acquisition & management Safety, security, emergency systems
Quality Management	Performance improvement Routine view: • outcomes, resources • utilization, risk management, compliance, satisfaction, needs, financial audit, accreditation, strategic & business plans standards, policies & procedures, data collection/documentation guidelines.
Communications/Marketing	Communication/Marketing strategies Materials Media liaison

RESOURCES	
Physical	Community
Environment Equipment Materials/supplies	Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public

APPENDICIES

Appendix L: Tools and Resources

Symptom Assessment and Management Tools/Resources

Tool	Website address
Brief Pain Inventory	www.ohsu.edu/ahec/pain/paininventory.pdf
Care Search, Palliative Care Knowledge Network	www.caresearch.com.au
Common Signs and Symptoms During the Last Days of Life	www.cancer.gov/cancertopics/pdq/supportivecare/lasthours/HealthProfessional/page3
Complementary and Alternative Medicine	http://nccam.nih.gov/health/whatiscam/ www.cancer.gov/cancertopics/cam
Edmonton Symptom Assessment System	www.palliative.org/PC/ClinicalInfo/AssessmentTools/ESAS.pdf
FICA (Faith, Importance, Community Address) Spiritual Assessment Tool	www.hpsm.org/documents/providers/End_of_Life_Summit-FICA_References.pdf
Fraser Health Hospice Palliative Care Symptom Guidelines	www.fraserhealth.ca/professionals/hospice_palliative_care/
Symptom Assessment and Management Tools	www.cancercare.on.ca/cms/One.aspx?portalId=1377&pageId76967
Collaborative Care Plans	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13618
The Victoria Hospice Society's Palliative Performance Scale	www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13380
World Health Organization Pain and Analgesic Ladder	www.chcr.brown.edu/pain/FASTFACTS3.pdf www.who.int/cancer/palliative/painladder/en/

Educational Resources

Canadian Association of Schools of Nursing- The Principles and Practice of Palliative Care Nursing and Palliative Care Competencies for Canadian Nurses	www.casn.ca/en/Whats_new_at_CASN_108/items/81.html
Canadian Virtual Hospice	www.virtualhospice.ca
Edmonton Palliative Care Program	www.palliative.org
End of Life Curriculum Project	http://endoflife.stanford.edu/eol_toolbox/intro_eol_toolbox.html
End of Life Nursing Education Consortium	www.aacn.nche.edu/ELNEC
Improving End of Life Care for Aboriginal Families Project	www.spheru.ca/research-projects/completing-the-circle-end-of-life-care-with-aboriginal-families/Improving%20End%20of%20LIfe%20Care%20for%20Aboriginal%20Families.pdf
International Hospice Institute and College	www.hospicecare.com
Learning Essential Approaches to Palliative Care (LEAP) Education	www.pallium.ca
National Action Planning Workshop on End-of-life Care	www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2002-nat-plan-palliat/index-eng.php
Health-care Professional End-of-life Educational Resources and Programs	http://palliative.info/pages/Education.htm
Promoting Excellence in End-of-life Care	www.promotingexcellence.org
Toolkit for Nurturing Excellence at End-of-life Transition	www.tneel.uic.edu/tneel.asp
Toolkit of Instruments to Measure End-of-Life Care	www.chcr.brown.edu/pcoc/toolkit.htm

Appendix M: Description of the Toolkit

Best practice guidelines can be successfully implemented only if there are adequate planning and resources available, organizational and administrative support, and appropriate facilitation. To this end, the RNAO, in collaboration with a panel of nurses, researchers and administrators, has developed the *Toolkit: Implementation of Clinical Practice Guidelines*, www.rnao.org/bestpractices/PDF/BPG_Toolkit.pdf, based on available evidence, theoretical perspectives and consensus.

The *Toolkit* provides step-by-step directions to individuals and groups in health-care organizations involved in planning, coordinating and facilitating implementation of any of the RNAO's clinical practice guidelines.

Specifically, the *Toolkit* addresses the following key steps regarding guideline implementation:

1. Identification of a well-developed, evidence-based clinical practice guideline.
2. Identification, assessment and engagement of stakeholders.
3. Assessment of environmental readiness for guideline implementation.
4. Identification and planning of evidence-based implementation strategies.
5. Planning and implementation of evaluation.
6. Identification and securing of required resources for implementation.

Implementing guidelines that result in successful practice changes and positive clinical impact is a complex undertaking. The *Toolkit* is a key resource for managing this process.

Notes

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INTERNATIONAL
AFFAIRS & BEST PRACTICE
GUIDELINES

TRANSFORMING
NURSING THROUGH
KNOWLEDGE

Clinical Best
Practice Guidelines

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