



CANADA

HEALTH STARTS AT HOME
LA SANTÉ COMMENCE CHEZ SOI

EVIDENCE-INFORMED BEREAVEMENT CARE

A PRIMER OF INTERVENTIONS
TOWARDS HEALTH SYSTEMS CHANGE

August 2012

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Greetings from VON Canada

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President and Chief Executive Officer
Victorian Order of Nurses Canada**



On behalf of the Victorian Order of Nurses (VON) Canada I am pleased to announce the release of *Evidence-Informed Bereavement Care: A Primer for Health Systems Change*.

We are particularly proud of this recent collaborative project. Our research scientist, Dr. Ariella Lang, led a pan-Canadian interdisciplinary team of researchers, clinicians and decision makers along with representation from Registered Nurses' Association of Ontario (RNAO) in the development of this document aimed at improving bereavement care that was co-funded by VON and the Canadian Nurses' Foundation Nursing Care Partnership Program. Although the original goal was to tailor two existing RNAO guidelines (Supporting Families through Expected and Unexpected Events (2006) and Establishing Therapeutic Relationships (2006)) into a bereavement context, it became increasingly apparent that a unique, topic specific package of approaches and interventions was needed.

Given that VON Canada has identified improving the delivery of quality services for bereaved families across the life span as a high priority, this collaborative compilation of evidence co-created from a knowledge translation (KT) perspective, is extremely timely and pertinent.

VON Canada has the vision and is committed to creating a global community of nurses who lead by using knowledge, scholarship, service and learning to improve the health of the world's people.

I look forward to the continued initiatives towards promoting best practices within home and community care. Bereavement touches us all and nurses are ideally positioned and equipped to offer proactive support and to help mitigate the potential health and social risks associated with grief following the death of a loved one.

Sincerely,
Judith Shamian, RN, PhD
President and Chief Executive Officer
VON Canada

Purpose and Scope of this Document

Primary bereavement care in nursing practice is central to the health and well-being of family members who experience the death of a loved one. This document is intended to describe optimal primary bereavement care, and identify the priorities, strategies and interventions for providing sensitive, appropriate and effective primary bereavement care. The term “primer” signifies a package of systems interventions that serve as a foundation and catalyst to improve care to individuals, families, and communities around the death of a loved one.

RNAO Best Practice Guidelines (BPG) entitled Supporting and Strengthening Families through Expected and Unexpected Life Events (2006a) as well as Establishing Therapeutic Relationships (2006b) are considered to be prerequisite and complementary documents to Evidence-Informed Bereavement Care: A Primer for Systems Change. The recommendations in these two guidelines reflect outstanding nursing practice. They are an essential foundation for effective primary bereavement care. A summary of the recommendations from both of these guidelines is provided in Appendix A.

It is anticipated that this document will be a valuable tool for all nurses as well as other health care providers involved in caring for bereaved family members and friends. More specifically, it is intended to be relevant:

- across **a variety of health care settings and situations** (emergency to community, acute to chronic, sudden to palliative);
- with **diverse populations**; and
- in **all types of death and bereavement experiences**.

This package of systems interventions is expected to support and ensure quality primary bereavement care and thereby promote the health of those individuals experiencing the death of a loved one. The purpose of this document is to create a comprehensive and current depiction of primary bereavement care; it is not intended to serve as a task-focused checklist for intervention or treatment.

Additional objectives of this primer are to:

- create opportunities for nurses to reflect on, challenge and evaluate their nursing practice with the bereaved;
- provide stepping stones for organizations to build, extend and focus their capacities in supporting primary bereavement care with families; and
- highlight the responsibility and potential of the nursing profession to identify the need for and impact of sensitive and effective bereavement care.

Bereavement Care – Research Study

This Bereavement Care Primer for System Change is the result of a peer-reviewed and nationally funded research study. Co-led by Drs. Ariella Lang and Fabie Duhamel, this team was comprised of researchers, clinicians and decision-makers from University of Ottawa, Université de Montréal, McGill University, McMaster University, Indiana University, Dalhousie University, and the Victorian Order of Nurses (VON) Canada.

This study, primarily funded by the Canadian Nurses Foundation's Nursing Care Partnership Program, in collaboration with RNAO and VON Canada, subsequently led to the development of this Bereavement Care Primer for Systems Change.

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We would like to thank the following individuals for their invaluable support in participant recruitment and data collection:

- At VON Canada Greater Halifax: Donna Hanczaryk, Pat Bell and Morah MacEachern
- At QEII Health Sciences Centre: Marianne Arab and Pauline Fowlie,

A very special thank you to Donna Hanczaryk, Coordinator Client Services and Palliative Care Community Support Services, whose passionate conviction was instrumental in facilitating the success of this project at VON's Greater Halifax site.

We are also grateful to all of the study participants for their thoughtful and insightful comments and to Serena Corsini-Munt and Kristine Iaboni for their project coordination, drafting, and editorial support.

Document Development Process

The purpose of this research study was to synthesize and develop a unique, topic specific package of approaches and interventions for primary bereavement care.

Expert Panel Meeting

An interdisciplinary expert panel (i.e., family nursing, pastoral care, family science, medicine, paediatric/family psychiatry and psychology) composed of six theory and practice experts in bereavement care from Canada and the United States was convened. These six experts, along with members of the extended research team, were purposefully selected for several reasons including: their immersion in clinical practice and research on this topic, their knowledge of the current evidence, and their leadership and capacity to perpetuate change as a result of their participation in this project.

One month prior to convening a two-day, face-to-face meeting of this expert panel, participants were sent a description of the purpose of the study, a summary of Lang's (2005) model entitled "*Promotion of Health and Well-being in Bereaved Individuals and Their Families*" and two RNAO guidelines to serve as best practice references of strength based approaches to working with families. With the principal investigator as the facilitator, members of the panel presented their knowledge, experiences and beliefs around grief and bereavement. Furthermore, consensus was reached on guiding principles and shared ideas of primary bereavement care in nursing. The panel determined key themes for recommendations within practice, education, research, policy, and community development for both nurses and organizations.

Literature Review

A literature review was undertaken to identify and explore central themes relating to bereavement, grief and bereavement care practices, including family-systems, crisis and communication theories relevant to caring for the bereaved. A search, including years 1982–2005, was conducted in MEDLINE, Cochrane Library, CINAHL, and PsycINFO, to identify peer-reviewed articles. In addition, key death/bereavement journals were hand searched. Grey

literature was identified through internet searches. The reference lists of selected articles also informed the review. Search terms included: bereavement, grief, bereavement care, bereavement interventions and grief interventions. Articles were included if relevant to nursing, nursing intervention and intervention in general. Articles were excluded if they did not relate to nursing scope of practice, and if the specific interventions required advanced practice expertise. Finally, experienced clinicians and researchers in the bereavement field were asked to identify important sources to be included in this review. The core concepts of Lang's (2005) model of "*Promotion of Health and Well-being in Bereaved Individuals and Their Families*", which is an evolving, integrated, evidence-informed conceptual framework for primary bereavement care in nursing also guided the literature review.

First Draft

The work of the expert panel provided the framework and key theme areas for the PRIMER that were then integrated with findings of the literature review. The first draft included 18 recommendation statements with detailed descriptions and examples for practice.

Focus Groups

Seven focus groups, each approximately two hours in length and consisting of six to eight participants each, were held separately with nurses (n=2), managers (n=1), and bereaved family members (n=4) to obtain comments about the *Bereavement Care Primer for Systems Change*. The focus group participants were drawn from the VON Greater Halifax, Nova Scotia area because of its provincial contract for providing home care services involving 160 nurses, and its active palliative and supportive care program (approximately 1400 palliative care visits/month). The focus group format provided a forum to elicit co-constructed views from various perspectives about the recommendations and how to best implement them within the context of bereavement, with consideration given to enabling and constraining forces.

One month prior to the focus group, participants were sent a draft of the document for review with some specific questions to consider. The same questions, along with any new issues that subsequently arose, were addressed during each focus group. Participants also had the opportunity to discuss how Lang's (2005) model could be made operational, to make suggestions for interventions related to primary bereavement care, and to propose recommendations for corresponding individual and family outcomes.

Nurses who worked ≥ 24 hrs/wk and provided care for ≥ 5 individuals requiring palliative care services and their families within the past year either at the QEII Health Sciences Centre or at VON Greater Halifax site were eligible to participate. For the purposes of this study, family was defined as the individuals who were directly involved with the individual receiving the palliative care and included those who had experienced the death of a family member six to 12 months before the study, and were 18 years of age or older. Managers from QEII Health Sciences Centre and VON Halifax, including senior directors, were eligible to participate. All participants were able to read and speak in English.

Nurses who met the inclusion criteria were invited to participate. From those who expressed interest in the project, focus group participants were purposefully selected to ensure variation in this sample including years of experience, practice setting (i.e., acute vs. home care). The VON branch manager in Halifax facilitated the identification of and contact with individuals/families who had lost their loved one 6-12 months earlier and for whom VON nurses had provided palliative care. To ensure variation, family members were selected for gender and their relationship with the deceased (e.g., spouse, sibling, etc.). Given their limited numbers, all managers/directors were invited to participate.

One year after the first round of seven focus groups, two to three invested and articulate participants from each of the original focus groups were purposefully invited to form a combined focus group. Participants from this recombinant focus group were asked to peruse and provide feedback on the revised recommendations that incorporated the comments and suggestions from the seven original focus

groups. The research team once again used coding, thematic analysis and descriptive content analysis to collate, synthesize and refine the data to transform the revised recommendations once more until consensus was reached.

Second and Third Draft Development

Based on the feedback from the focus groups, expert panel members and the extended research team, suggestions were integrated into the document for the second and third drafts.

Stakeholder Review

This near final draft was then submitted to external stakeholders accessed through RNAO's network for review and feedback. Stakeholders represented various health care professional groups, clients and families, and professional associations. These stakeholders were provided with specific questions for comment, as well as the opportunity to give overall feedback and general impressions. These stakeholders are acknowledged for their contribution on page 61 of this document.

Final Draft Development and Publication

The feedback from stakeholders was compiled and reviewed by the research team. Discussion and consensus resulted in revisions to the draft document based on this feedback. In addition senior members of the RNAO International Affairs and Best Practice Guideline Program and Health and Nursing Policy Department also reviewed and provided feedback on the document.

Bereavement Care Literature Review Summary

Literature Review

A summary of the highest level of scientific evidence about a particular topic was a requirement of earlier conceptualizations of evidence syntheses, perhaps at the “relative neglect of other forms of evidence in the delivery of health care” (Rycroft-Malone, Seers, Titchen, Harvey, Kitson, & McCormack, 2004, p. 83). Nonetheless reflections in recent decades about what constitutes evidence have broadened the evidence discussion in particular as it relates to evidence informed interventions. Evidence can be defined as an aggregate of understanding obtained from many different sources that has been tested and found tenable (Higgs & Jones, 2000). Even though some “higher level” research evidence about grief and bereavement care interventions from practice disciplines other than nursing exists, there is a dearth of literature about primary preventive types of interventions. Therefore, seeking and including other sources of evidence was a central and purposeful objective of this project. Recognition of the value of multiple sources of evidence is demonstrated by the integration of a literature review with expert knowledge and experience of clinicians, researchers, administrators, educators, as well as care recipients. In considering the many ways in which evidence can be defined, and the many sources from which it can be derived, this bereavement care primer was developed in a comprehensive manner which harnessed a broadened view of evidence as well as a knowledge translation strategy.

The majority of the evidence utilized to develop this primer is based on expert opinion. The recommendations were developed through a consensus process and based on the experience of the expert panel.

The expert panel based the recommendations on:

- **Professional knowledge / clinical experience:** This includes knowledge derived from professional practice and life experience.
- **Local data and information:** This includes but is not limited to, audit and performance data, personal

narratives, local and national policy.

- **Care recipient’s (bereaved individual) experiences and preferences:** Encompasses the interaction of the bereaved personal knowledge and experiences with the care provided.

Historical Portrait of Grief and Bereavement

Losing a loved one is often described as one of the most challenging life experiences. Experiences of loss, grief and bereavement are unique, dynamic and wide-ranging in spite of the ubiquitous presence, commonality and universality of death in our lives (Moules, 1998; Moules, Simonson, Prins, Angus & Bell, 2004; Neimeyer, 2001). Although death – both expected and unexpected – is a certainty, family members’ responses are not. This is because “no two of us experience bereavement in identical ways” (Attig, 1996, p. 56). Nevertheless, grief is present in recognizable patterns around which guiding principles may be recommended but not prescribed.

Grief and bereavement have been explored and studied through the ages. Scientific exploration of bereavement “has already passed through a number of identifiable generations, each being characterised by attention to a distinct set of important issues, theoretical advancements, and unique implications for society” (Stroebe, Hansson, Stroebe & Schut, 2001, p. 3). Freud’s (1917/57) *Mourning and Melancholia* is touted as one of the earliest influential accounts of grief in which he described mourning as a process of “detaching oneself from the deceased” (Balk, 2003, p. 833), that grief “is a job of psychological work that we neglect at our peril” (Parkes, 2001, p. 26), and that bereavement may be a cause of depression. Explorations of grief and bereavement since that time have ranged from conceptualizations of grief as “normal” with deviations from normal (Lindemann, 1944), to grief as a cause of psychiatric problems (Parkes, 1965), to several theories involving anticipated or expected stages, tasks or processes of mourning (Bowlby, 1961; Bowlby & Parkes, 1970; Kübler-Ross, 1969; Rando, 1993).

Contemporary trends and themes have emerged in recent decades on grief and bereavement research. The Center for the Advancement of Health (2003) published the *Report on Bereavement and Grief Research* which states that:

- There is not a dominant discipline or profession, nor a leading theory in grief and bereavement research;
- No common grieving process has been identified – responses to loss are broadly variable;
- There is a distinction between “normal grief” and “complicated/pathological grief”;
- Positive adaptation to bereavement has been associated with bereaved individuals maintaining psychological and/or emotional bonds/relationships with the deceased;
- Positive emotions and/or absence of distress for those who experience a death can be an expected part of bereavement;
- Bio-physiological bereavement responses (in particular, neuroendocrine, immunologic and sleep responses) are being identified, measured, considered and studied in terms of their impact on bereavement experiences and outcomes;
- Grief is now understood less as a medical problem, and more as an individual and societal event with possible health implications; and,
- There is a need for improved linkages between bereavement research and practice in order to determine and promote the most appropriate and meaningful care for bereaved family members.

Bereavement is “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).

Contemporary conceptualizations of grief depict it as unpredictable, unique, unavoidable, ever-changing, ongoing, irresolvable, and life-long – but certainly still a mystery that [continues to] pervade... our human condition” (Attig, 1996, p. 15; Moules et al., 2004; Moules, 1998).

Perspective on Bereavement Care

Shared Ideals of the Expert Panel

The expert panel members, who collaborated to determine the foundational tenets of this guideline through consensus, are health care professionals from various disciplines with expertise in bereavement care. The following is their shared collection of beliefs and assumptions about grief and nursing, which are foundational concepts for this document:

- Grief:
 - ⇒ Is a lifelong and life changing experience
 - ⇒ Involves sorrow and celebration
 - ⇒ Is a spiritual and meaning-making experience
 - ⇒ Is relational (internally in the bereft; externally between families, as well as between individuals/families, social networks, communities)
 - ⇒ Shows itself in a range of experiences and responses
 - ⇒ Does not progress through a series of stages and phases that end in closure
 - ⇒ May not heal and may not be taken away or resolved.
- Family members may not know about, want to, or know how to seek bereavement care.
- Family members often perceive grief as something to be endured intra-personally.
- People and society as a whole hold beliefs about death and grief that can facilitate or constrain bereavement experiences. For example, a commonly held but perhaps constraining belief is that *time heals all wounds*.
- When nurses enter into relationships with family members around death, they also enter into relationships with the grief experiences of the family members, in addition to their own personal experiences with grief.
- Nurses, like most members of society, are often not comfortable with death and with those who are bereaved; nurses need to surmount their unease and have confidence in the merit of their role and the potential impact of their caring interventions.
- Bereavement care does not just begin *after* a death – it includes the time leading up to, surrounding, and

following the death.

- There are no prescribed stages of grief and there is no “right” way to grieve a death. Every individual has their own unique ways to manage and cope with the death of a loved one.
- It is critical that nurses be aware of their own personal losses and how the experiences of the bereaved can impact on these losses, as well as their ability to provide appropriate care.

What Do We Mean by “Primary Bereavement Care”? Why is it important?

Caring for the bereaved is imperative in order to support and promote the health of individuals, families and communities. Primary bereavement care is defined as health care professionals capturing and creating opportunities to be with and support individuals/families in their experiences of grief and mourning surrounding the death of a loved one. These supportive practices are indicated for all bereaved individuals/family members, to differing extents (Joanna Briggs Institute; JBI, 2006), whether it is five minutes in an Emergency Room or five months in palliative care. Bereavement care is often focused on pathology or difficulties experienced by the bereaved and is frequently provided by bereavement care specialists (e.g., psychologists, psychiatrists, social workers, etc.). In contrast, the emphasis of primary bereavement care is on prevention of negative sequelae and on health promotion for the bereaved. This primer is a tool designed to support all nurses and other health care professionals faced with bereaved individuals and families, regardless of where the death of a loved one occurs (e.g., emergency department, labour and delivery, geriatrics, paediatrics, medical/surgery, etc.). Primary bereavement care may prevent future morbidity, and serves to direct those in need of specialized bereavement care to appropriate services. Primary bereavement care interventions and activities must be implemented at both the provider and organizational levels. In keeping with the scope and audience of this primer and for purposes of this document, bereavement care constitutes

primary prevention and/or primary care nursing interventions. These supportive nursing practices are indicated for all bereaved family members regardless of the type of loss, the cause of death or where the death occurs.

Contemporary conceptualizations of grief and bereavement are less frequently framed through a pathological lens. Also, most people do not seek health care or perceive their experience of bereavement to be one requiring professional help, despite the possible intensity of suffering. However, there is a documented need for nurses to attend to the bereaved (Lang, Gottlieb & Amsel, 1996; Lang & MacLean, 2007; JBI, 2006; Williams, O'Brien, Laughton & Jelinek, 2000). In addition, family-systems, crisis and communication theories provide a substantial empirical and theoretical evidence base for primary bereavement care practices (Boss, 2002; Stroebe et al., 2001; Tedeschi, Park & Calhoun, 1998; Wright & Leahey, 2005). For most bereaved individuals, care in the form of general, supportive types of interventions that are appropriate and meaningful around the time of death, regardless of setting, can be provided by all nurses. For others, additional care may constitute more in-depth, focussed, secondary and tertiary prevention activities that are appropriate for “at risk” family members, and for which specialized education and practice are necessary. A key component of this type of care is to adapt to the uniqueness and individuality of the experiences and needs of bereaved family members.

Empirical studies have revealed the deleterious effects that the death of a loved one can have on the physical and emotional health of family members (Christakis & Allison, 2006; Christakis & Iwashyna, 2003; Dimond, Caserta & Lund, 1994; Mekosh-Rosenbaum & Lasker, 1995; Wortman & Silver, 1989), including an increased risk for psychiatric illness (Siegel, Hayes, Vanderwerker, Loseth & Prigerson, 2008) and hospitalization (Li, Laursen, Precht, Olsen & Mortensen, 2005). Although it is still unclear which groups of bereaved individuals are more vulnerable, there is agreement that the death of a loved one affects the health and well-being of all who are bereaved (Lang & Gottlieb, 1993; Stroebe et al., 2001). There is evidence that the bereaved suffer from a range of physical, emotional and social issues and concerns (e.g., elevated risks of depression, increased somatic complaints, more use and

abuse of medication and mood-altering substances, and increased disability days; Stroebe et al., 2001). Given the evidence of potential negative health impacts following the death of a loved one, and the documented need for support, primary bereavement care must be integral to other health care agendas and services and particularly to nursing practice.

Why is Primary Bereavement Care a Fitting Role for Nurses?

For nurses, care is at the forefront, people are the focus, the approach to health and illness is multidimensional, and evidence-informed practice occurs across a diversity of settings and situations. This is what so nicely defines the potential pivotal role for nurses in primary bereavement care. Nurses are close to those who die and to those loved ones who remain. They are also a constant presence across a variety of settings and situations. Foundational aspects of nursing as a knowledge-based caring profession position nurses as providers of primary bereavement care.

Contrary to the popular belief that only certain professionals with specialized education and training can engage in primary bereavement work with families, nurses also play a definite and important role regardless of their work setting. Although there are situations where families may require more long-term and more expert interventions, this does not preclude the value of nurses' role surrounding the death.

It is also imperative to highlight that the “work” of primary bereavement care is not an additional task for nurses to perform in our present resource-challenged health-care system. Nurses are often already doing many things that are helpful to bereaved families as part of their daily nursing activities. The recommendations in this guideline build upon these existing aptitudes and practices, and offer additional support and guidance in the hope of making the experiences of care for nurses and families increasingly positive. Hence, this guideline is intended to galvanize nurses' capacity to initiate and provide primary bereavement care to individuals and families.

Framework for and Foundation of the Package of Systems Interventions

Conceptual Underpinnings of Primary Bereavement Care in Nursing – Lang’s Model for The Promotion of Health and Well-Being of Bereaved Family Members (2005)

Dr. Ariella Lang is the Principal Investigator and Project Team Leader for this bereavement care practice guideline research project. Her (2005) model serves as an evolving, integrated, evidence-informed theoretical framework for primary bereavement care in nursing. This model was developed as part of Dr. Lang’s program of research on the promotion of health and well-being in bereaved family members, as well as in support of VON Canada’s national initiative to prioritize nursing care of the bereaved.

This model has been included near the beginning of this document to set the theoretical tone for this primer. All stakeholders, and especially nurses and health and social service organizations, are encouraged to consider their contributions to, and responsibilities in primary bereavement care, within the context of this framework.

Lang’s model is influenced by Boss’ (2002) *Crisis Model of Family Stress* (CMFS), which is based on Hill’s (1958) *ABC-X Model of Family Stress Theory*. Boss’ CMFS focuses on three variables, which remain a foundation of current family stress theory. The three variables are: **A** – the provoking event or stressor; **B** – the resources or strengths of family members and the family as a whole; **C** – the meaning attributed to the event. **X**, is the response (coping or crisis) of the family members to the stressor, and is impacted by resources and attributed meanings.

Lang’s model has evolved from the CFMS, to a focus on Health and Well-Being as the outcome (**X**). Bereavement as **A**, Resources as **B**, Perceptions and Meaning Making as **C**. In addition to these modifications, the element of the “family members as the focus of care” has been added to the centre of the diagram in order to reflect the importance of family members in bereavement.

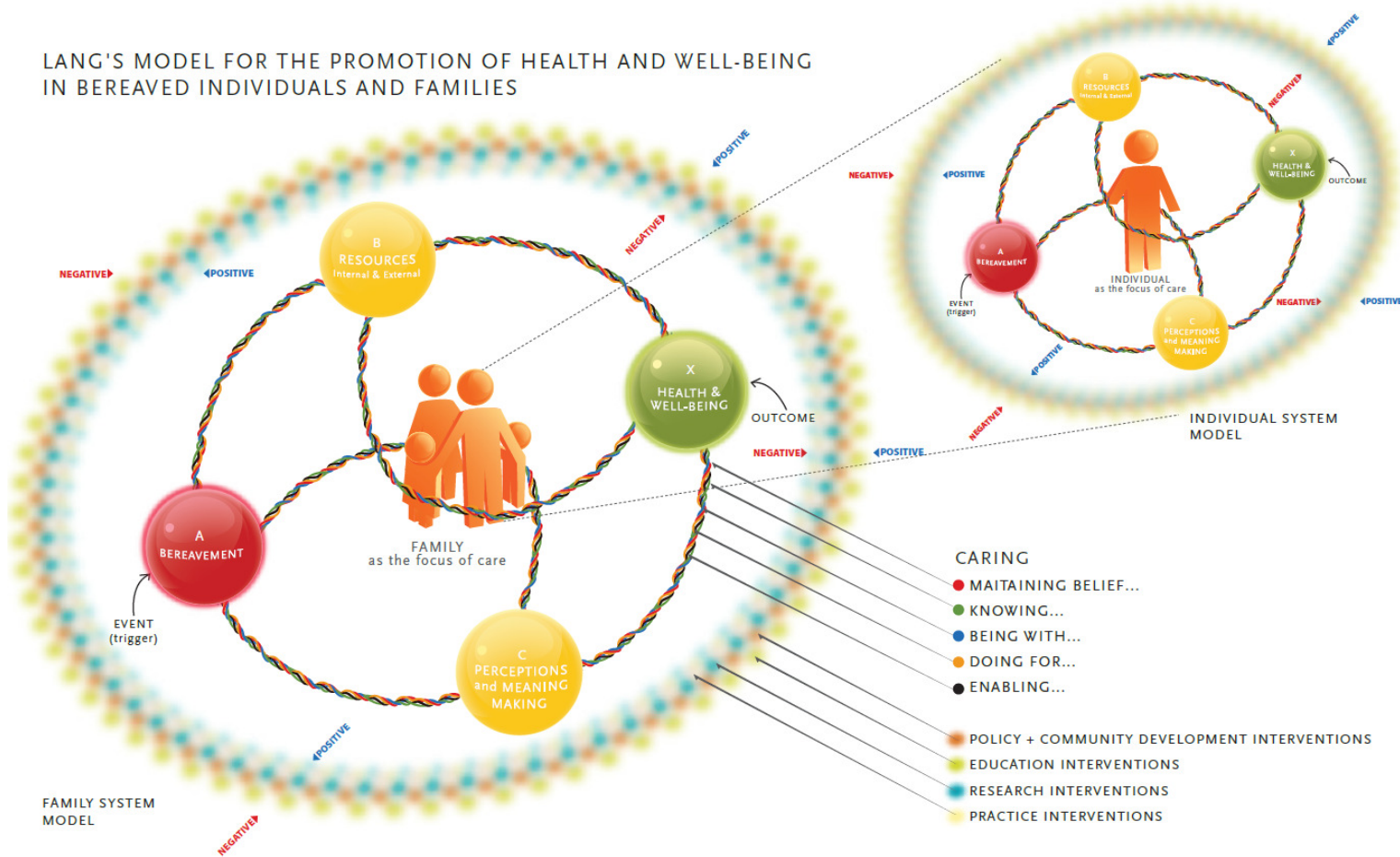
See Figure 1 for an illustration of Lang’s model of *Promotion of Health and Well-being in Bereaved Individuals and their Families*.

EVIDENCE-INFORMED BEREAVEMENT CARE: PRIMER OF INTERVENTIONS TOWARDS HEALTH SYSTEMS CHANGE

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Figure 1: Lang’s model for the Promotion of Health and Well-being in Bereaved Individuals and Families

LANG'S MODEL FOR THE PROMOTION OF HEALTH AND WELL-BEING IN BEREAVED INDIVIDUALS AND FAMILIES



Description of Model Components

(A) – BEREAVEMENT

The bereavement experience is “the event or the stressor”. It is an experience of sufficient magnitude to bring about change in the family system, and has the potential for producing stress (positive or negative) for family members. The bereavement experience depends on perceptions, resources and the context in which the stimulus occurs. Stroebe and Schut’s (1999) *Dual Process Model of Coping* with bereavement is significant to this model. It suggests that grief waxes and wanes throughout a person’s lifetime, and that dealing with the loss and secondary consequences of a death are potential sources of anxiety. According to Stroebe and Schut’s model, bereaved family members do not achieve closure after a death, but rather strive to reconcile a new normal life without the physical presence of their loved one. There is also a significant variation in the types of grief that are experienced, as well as in their intensity, duration and expression (Christ et al., 2003).

(B) – RESOURCES (Internal and External)

Resources, both internal as well as external, are potential “individual/personal and collective strengths”. They may be characteristics, traits, competencies, or means of a person, family or community.

Lang’s model includes the concept of hardiness as the internal resource for coping with grief. Hardiness is an important predictor of health in bereaved individuals (Lang, Goulet & Amsel, 2004). Hardiness is manifested in individuals’ inherent potential to:

- Gain a sense of personal control over the outcome of life events and hardships;
- Develop an active orientation toward meeting the challenges brought on by a loss; and,
- Maintain a belief in the ability to make sense of one’s own existence following such a tragedy (Lang, Goulet, Aita, Giguère, Lamarre & Perreault, 2001).

Marital and social supports are mainstays of external resources for bereaved individuals. External resources also help to protect against psychological distress in stressful situations, such as bereavement, and mediate some of the stress of important life transitions (Rubin & Malkinson, 2001; Schaefer & Moos, 1998). Variations and examples of such external supports include:

- Family resources (i.e., cohesion and adaptability; Olson, 2000; Olson & Gorall, 1993);
- Level of marital satisfaction (Kelly & Conley, 1987; Kurdek, 1995);
- Degree of family functioning (Davies, 1986; Sawin & Harrigan, 1994);
- Family organization (Moos & Moos, 1983);
- Communication (Caelli, Downie & Letendre, 2002; Kavanaugh & Paton, 2001; Saflund, Sjogren & Wredling, 2004; Satir, 1972); and,
- Community resources (i.e., characteristics, competencies, and means of persons, groups, and institutions outside of the family).

(C) – PERCEPTIONS AND MEANING MAKING

Perceptions and meaning making encompass the idea of family members’ “appraisal” of the event and its subsequent impact on them and their relationships. The following points highlight some important nuances about perception and meaning making:

- Perception is a powerful factor that is instrumental to coping, and in turn, health and well-being (Lang et al., 2004).
- Family members’ perceptions and the meanings that they attribute to the death and their bereavement experiences may be different from each other, and are often different from that of an objective outsider (Becvar, 2001; Boss, 2002). It is important to recognize that although a person can be alone in their grieving, we must be aware that family, friends or others around them often influence that individual’s grieving process.
- Family members, individually and collectively, attribute their own meaning and reality to the event, regardless of the facts (Boss, 2002).
- There is an inherent need to find meaning after a significant loss; it becomes embedded in the bereaved individual’s remaining existence, is always subject to change and is redefined as life experiences offer new information or insights (Neimeyer, Baldwin & Gillies, 2006).
- The development of positive meaning in bereavement-related events brings about or enhances positive affect. Being able to interpret events or situations positively is effective in creating an optimistic state of mind and reducing stress (Calhoun & Tedeschi, 2001; Neimeyer, 2000).

(X) – HEALTH AND WELL BEING

From a nursing perspective, health and well-being are “the outcomes”. Health and well-being have both individual/personal, as well as relational elements that are influenced by the interplay between bereavement, resources and meaning making. Similarly, health and well-being also impact these other elements of the model in a responsive and dynamic fashion. Furthermore, health and well-being are the desired outcomes of prevention and health promotion for individuals, couples, families and communities. The nature and level of health and well-being are assessed in the context of what is appropriate and optimal for a particular individual, family or community. Health and well-being are based on individual and collective choices, judgements and perceptions.

FAMILY – THE FOCUS OF CARE

Family, as the focus of care, is the core, foundational, and anchoring element of the model. Family is the context in which individuals learn about health and how to mobilize resources, strengths and potentials in order to reach their goals (Feeley & Gottlieb, 2000). A family-centered approach to nursing practice, where nurses and families work in shared partnership for health, is a core competency for exemplary nursing.

CARING

Caring is the connective and flexible cord woven throughout that unifies the elements of the model. The strands of the cord represent core competencies for primary bereavement care nursing interventions. Swanson’s (1993) *Caring Theory* was included in the model specifically because of its pertinence to the topic at hand. Her research is founded on work with a bereaved population. *Caring* is described as “a nurturing way to relate to a valued other, towards whom one feels a personal sense of commitment and responsibility” (Swanson, 1991, p.161). It follows that, nursing is “informed caring for the well-being of others” (Swanson, 1993, p. 352).

Swanson (1993) characterizes caring as being composed of five overlapping processes: maintaining belief; knowing, being with; doing for; and, enabling.

(1) Maintaining Belief

A fundamental belief in:

- Family members and their capacity to make it

through events and transitions, such as the death of a loved one, and to face a future with meaning; and,

- A future where the life and the death will have a peaceful, permanent meaning in day to day existence of family members.

(2) Knowing

An informed understanding of events in terms of how they have meaning to the lives of others:

- General: health, loss, bereavement, etc;
- Specific: situation and family (type of loss, spiritual or cultural context, etc.); and,
- Self: willingness of the nurse to know another’s reality; capability of the nurse to contain his/her needs and to focus on the client’s lived reality.

(3) Being With

Consists of:

- Emotional presence;
- Time giving;
- Authentic presence;
- Attentive listening;
- Reflective responses;
- Availability and ability to endure; and,
- Sharing another’s reality.

(4) Doing For

Is about:

- Comforting bereaved family members;
- Anticipating their needs;
- Performing competently and skilfully;
- Protecting them from undue harm;
- Preserving their dignity; and
- Providing safe arenas for people to bring about their own healing.

(5) Enabling

Denotes:

- Facilitating passage through transitions and unfamiliar events, such as death and bereavement;

- Coaching and clarifying;
- Maintaining a focus on important issues;
- Offering feedback; and
- Validating the others' realities.

Informed by these caring processes, nurses – the caring experts – are the clinicians who hold the advantaged position of presence surrounding the death of a loved one and the family members' ensuing grief. Therefore, nurses are the ones who can integrate pivotal yet possibly brief interventions based on these pillars of caring theory.

Caring is the foundation on which all bereavement care is predicated and is the underpinning of the primer recommendations.

SYSTEMS INTERVENTIONS FOR PRIMARY BEREAVEMENT CARE IN NURSING

Both the nurse (as the provider of primary bereavement care), as well as health care organizations and academic institutions (as supporting the nurse), must be the best practice “participants” in providing interventions to bereaved individuals and families. Each group has responsibilities across four categories or domains of interventions: practice, education and continued professional development, research, as well as policy and community development. This is portrayed by the rings surrounding the family and/or individual system model. This format acknowledges the responsibility that both the individual nurse and the individual organization have in primary bereavement care. It also highlights that neither is in isolation of the other – in their commitment to providing excellent care to bereaved family members. Pro and counter forces to system interventions are also part of Lang's model. These are represented by the opposing arrows pointing to the outer rings of interventions. These forces act on the health-promoting interventions and may be social, emotional, organizational, societal, spiritual, cultural, political, professional, ethical, personal, etc. in nature. Thus, the four domains of interventions are targeted at maximizing the pro forces while minimizing the counter forces.

Organization of Primary Bereavement Care Systems Interventions

The Primer interventions are organized and structured into four separate, but interrelated categories (See Figure 2):

- (1) Practice
- (2) Education and Continuing Professional Development
- (3) Research
- (4) Policy and Community Development

The summary of all the system interventions are presented in figure 3, in keeping with this format.

Figure 2: Structure of Primary Bereavement Care Interventions

PARTICIPANTS	CORE DOMAINS OF INTERVENTIONS			
PROFESSIONAL NURSE <i>Providing bereavement care</i>	PRACTICE	EDUCATION & CONTINUING PROFESSIONAL DEVELOPMENT	RESEARCH	POLICY and COMMUNITY DEVELOPMENT
ORGANIZATIONS (HEALTH CARE & ACADEMIC INSTITUTIONS) <i>Supporting the nurse</i>	PRACTICE	EDUCATION & CONTINUING PROFESSIONAL DEVELOPMENT	RESEARCH	

Figure 3: Summary of System Interventions

Nurse Practice Interventions

	Intervention
1	Proactive nursing practice includes bereavement care with family members.
2	Nurses acquire the knowledge, skills, attitudes and aptitudes to approach primary bereavement care with compassion. Competent nursing practices in primary bereavement care for family members include these central elements. Nurses: actively and openly acknowledge and validate the death of a loved one and the experience of bereavement; are emotionally and authentically present; consider the family as the focus of care, in the context of a larger system; are attentive to the narratives of family members about their experiences of loss and bereavement; recognize that bereavement care is based on effective communication; explore the family members' main concerns; identify, acknowledge, promote, and reinforce family members' strengths and potentials; and, provide appropriate and discerning anticipatory guidance about grief reactions and bereavement experiences.
3	Nurses ensure continuity of care for the bereaved.

Organizations Practice Interventions

	Intervention
1	<p>Organizations value and support primary bereavement care for family members. This is reflected through creating and fostering environments that are conducive to bereavement care by:</p> <ul style="list-style-type: none"> Ensuring appropriate resources (time, staffing, experts/teachers, physical space, funds); Developing, implementing and sustaining primary bereavement care-centred initiatives and policies; and Building performance objectives.
2	<p>Organizations recognize and support the nurses who provide primary bereavement care. This is reflected by:</p> <ul style="list-style-type: none"> Acknowledging and appreciating the nurse’s wellbeing as vital to successful primary bereavement care; Ensuring visible nursing leadership that establishes and maintains mechanisms to promote open conversation about primary bereavement care between nurses and other professionals as well as with all levels of management; Providing ongoing opportunities for education related to best practices; and Identifying and addressing barriers and facilitators to providing primary bereavement care.
3	<p>Organizations ensure continuity of care for the bereaved by building and sustaining connections and relationships with other health and human services.</p>
4	<p>Evidence-informed primary bereavement care can be successfully implemented where there are adequate planning strategies, resources, organizational and administrative supports and appropriate facilitation of uptake among clinicians. An effective organizational plan for implementation includes:</p> <ul style="list-style-type: none"> An assessment of organizational readiness and barriers to implementation, taking into account local circumstances; Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process; Ongoing opportunities for discussion and education to reinforce the importance of best practices; 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; and Opportunities for reflection on personal and organizational experience in implementing primary bereavement care.

Nurse Education and Continuing Professional Development Interventions

	Intervention
1	Nurses develop, nurture and evaluate an ongoing awareness of themselves in relation to bereavement and primary bereavement care, both personally and professionally.
2	Nurses are committed to ongoing professional development of their knowledge, skills, attitudes, and aptitudes in primary bereavement care.
3	Nurses should be aware and attend to their own wellbeing.

Organizations Education and Continuing Professional Development Interventions

	Intervention
1	Academic nursing programs (entry-level and advanced) include education about bereavement and primary bereavement care.
2	Organizations include education about bereavement and primary bereavement care in all orientation and continuing nursing education initiatives, regardless of practice settings (i.e., emergency, obstetrics, medical/surgical, out-patient clinics, hospices, long term care settings, chronic care, etc.).
3	Organizations utilize <i>Evidence-Informed Bereavement Care: A Primer for Systems Change</i> for quality and safety improvement initiatives.

Nurse Research Interventions

	Intervention
1	Nurses stimulate and advance research about bereavement and primary bereavement care as an integral part of their daily practice.
2	Nurse researchers who study bereavement and primary bereavement care seek opportunities to share research outcomes and new knowledge, and their applicability to the practice setting. Nurse researchers also seek opportunities to listen to and learn from the voices and experiences of practicing nurses.

Organizations Research Interventions

	Intervention
1	Organizations assist in developing and advancing research about bereavement and primary bereavement care.

Nurses and Organizations Interventions/ Policy and Community Development

	Intervention
1	Nurses and organizations, in partnership, advocate for changes at the regional provincial/territorial and national levels.
2	Nurses and organizations, in partnership, aim to support the health of bereaved individuals, families and communities by facilitating and promoting: Inter-sector collaboration (i.e., between acute care, long term care, and home care, between health care organization and non-health care organizations, etc.), and Inter-professional and stakeholder collaboration.

Nurse: Practice Interventions

1. Proactive nursing practice includes primary bereavement care with family members.

There is a prevalent misperception that primary bereavement care is a specialized area of health care that requires advanced training and knowledge. In addition, dying, death, loss and grief are not topics that are frequently or easily discussed in personal or professional domains. However, primary bereavement care is something that all nurses can (and must) do in all settings and under all circumstances.

Nurses already possess many of the necessary practice skills for working with the bereaved. As such, this guideline is a tool that is designed to support, strengthen and optimize the existing, but often unrecognized or underappreciated, capacity for compassionate primary bereavement care amongst nurses. Excellence in primary bereavement care must be founded on an attitude for embracing nursing's capacity for these activities and initiatives. This attitude can be bolstered by the fact that nurses are the health care providers who are closest to, and most constantly present for the bereaved. Primary bereavement care is an opportunity to have tremendous impact on the health of individuals, families and communities.

It's easy to say: "I didn't have time," "The timing was wrong" or, "There is never a good time for death." However, it is up to nurses to proactively make time. More prolonged and in-depth time may be needed for this kind of work under certain circumstances. Nonetheless, compassionate care of the bereaved can occur in brief moments and opportunities. During these same moments, much good or much harm can be done.

A common nursing situation is pain management requirements of a post-operative patient. It is inevitable that there will be post-operative pain and that the nurse will attend to the discomfort. Similarly, the death of a significant other will cause grief and distress. Nurses must learn to anticipate and actively engage with family members (Hallgrimsdottir, 2000) to provide meaningful, health-

promoting support around the circumstances of death as part of their repertoire of standard care.

Clinical Exemplar 1:

Karen was a new nursing graduate who had been working on a medical floor for six months. She had been taking care of 45-year-old Sushila for the past two weeks after she was transferred from the CCU. Sushila had gone into cardiac arrest during the night and died after numerous attempts were made by doctors and nurses to revive her. Her husband was notified and would be arriving at the hospital soon with their two children, ages 20 and 22, as well as her mother.

Karen was feeling very anxious about what she would do and say when the family arrived since she was not an expert in bereavement care. She felt she really needed some advice and went to the Clinical Nurse specialist Jasmin who had 15 years of experience in bereavement care. Jasmin said to Karen "You need to trust your skills and abilities as a nurse. I've seen you work with your patients on the floor and you show them great compassion and caring. You are also a great listener." Karen responded by saying, "But I have never spoken to anyone about death and am feeling very uncomfortable." Jasmin said, "In our society and in the hospital, I agree, we don't talk about death very much. Many of us feel that we are on our own when dealing with families and bereavement. We need to talk about it more, so I'm glad you came to talk to me. When you meet the family, just remember it is important to be able to clearly acknowledge the death. You could start by saying you are sorry for the death of Sushila and that it must be very hard for them. The next step is to listen and allow the bereaved family members to talk. The skill of listening is very powerful and therapeutic for families, as they will know that you are there supporting them. Your compassion and caring will easily come through. Just being there and allowing family members to grieve in whatever way they want is something I know you will be able to do." Karen said, "Thank you, I feel better knowing I'm not alone. I know it is something I want to be able to do, but I am just a bit scared."

2. Nurses acquire the knowledge, skills, attitudes, and aptitudes to approach primary bereavement care with compassion. Competent nursing practices in primary bereavement care for family members include these central elements.

Nurses:

- a) Actively and openly acknowledge and validate the death of a loved one and the experiences of bereavement;**
- b) Are emotionally and authentically present;**
- c) Consider the family as the focus of care, in the context of a larger system;**
- d) Attentive to the narratives of family members about their experiences of loss and bereavement;**
- e) Recognize that primary bereavement care is based on effective communication;**
- f) Explore the family members' main concerns;**
- g) Identify, acknowledge, promote and reinforce family members' strengths and potentials; and,**
- h) Provide appropriate and discerning anticipatory guidance about grief reactions and bereavement experiences.**

a) Nurses actively and openly acknowledge and validate the death of a loved one and the experiences of bereavement.

Acknowledging means that words, attitudes and actions, which are selected for their appropriateness to the circumstances and to the bereaved family, reflect that the nurse openly recognizes and clearly addresses the death of a significant other (Rycroft & Perlesz, 2001). It is about letting family members know that their grieving is valued, appreciated and understood (Ujda & Bendiksen, 2000).

Acknowledging the death assures families that the nurse is willing and able to be there for them – not only physically, but also through a message of availability and ability to endure with the other. Validating means that the nurse endorses and legitimizes that bereaved family members have a range of anticipated reactions and responses to the death of a loved one (Becvar, 2001). Normalizing grief involves communicating that there is no one “right” process of grieving, and that a range of grief responses can be

expected (Egan & Arnold, 2003).

Part of acknowledging and validating the death and the experiences of bereavement is recognizing the possible presence of suffering. Suffering can take many forms, and can manifest in varying levels of intensity.

Clinical Exemplar 2:

Pam is a community-based nurse. During a follow up home visit, Pam found 80-year-old Alice at home by herself, being very quiet and she appeared to have been crying. Alice's husband had died two weeks previously after receiving palliative care for the past few months during the end stages of cancer. During her visit, Pam said, “How have you been doing, Alice?” Alice's eyes welled up with tears as she looked at the nurse and said, “I can't stop crying and I don't know what to do with myself. I'm not sleeping and I can't seem to do much of anything.” Pam actively listened to Alice describe what her days were like. Pam recognized that what Alice was describing was part of the normal grieving process. Pam said, “Alice, what you're feeling is what many people feel at this time. You might also experience a loss of appetite and low energy. You might also find that you are very sensitive to others who are trying to be helpful, but may not come across as such, with comments like ‘He's in a better place.’ These are all normal reactions that can be part of losing a loved one. It's only been two weeks. Give yourself time. Although I will be calling you in a week or so to see how you're doing, please do not hesitate to call me.”

b) Nurses are emotionally and authentically present.

This is based on the nurse's belief that she/he is doing work that is fundamentally helpful, important and meaningful for bereaved family members. Emotional and authentic presence (Greenstreet, 2004; Swanson, 1993) may be fostered through developing a perspective of:

- Confidence that his/her bereavement care work has the potential to make a meaningful difference; and,
- Hopefulness that family members can make it through and experience a sense of personal growth as a result of the life-changing experience of death.

Key components of presence are:

- Deep listening (Greenstreet, 2004);
- Making time, despite "no time";
- Demonstrating empathy (Meert, Thurston & Briller, 2005);
- Allowing comfortable silence; and,
- Allowing therapeutic and professional touch. (Edlich & Kübler--Ross, 1992; Hamilton, 1988; Janzen, Cadell, & Westhues, 2004; Jordan & Neimeyer, 2003).

Regardless of whether it is a couple of minutes or over several weeks and months, through emotional and authentic presence (Swanson, 1993), the nurse can have long-term and memorable implications for family members in the face of grief.

Clinical Exemplar 3:

Take a moment to refer back to Pam's case. Although Pam could only stay for half an hour, she made sure she was attentive and genuine in her conversation with Alice. Alice squeezed Pam's hand at moments when Pam thought it appropriate to offer her hand to connect empathetically. Throughout the conversation Pam encouraged Alice to talk about how she was feeling physically, emotionally and spiritually. At the end of the visit Alice took a deep breath and looked more relaxed. She told Pam that she did feel better and thanked her for listening.

Clinical Exemplar 4:

Jennifer, an emergency room nurse, is working in the trauma unit where a teenager has just died. Jennifer is a strong advocate of primary bereavement care. Jennifer notices the bereaved parents and pauses for a moment to look the bereaved parents in the eye, places a gentle hand on their shoulders, and says "I am so sorry for your loss. It must be a terrible shock for you and your family". This simple act conveys explicit acceptance of expressions of disbelief, distress and anguish. In contrast, in the same moment, another nurse Tara, who is uncomfortable with bereavement care, unknowingly or perhaps inadvertently turned away and avoided the death and the suffering of the family by resisting eye-contact or not lingering in the room.

c) Nurses consider the family as the focus of care, in the context of a larger system.

Considering the family as the focus of care is fundamental to working with the bereaved. For most, this is the context in which the death and bereavement is experienced.

Some important points to remember about families are that:

- Family structures and family processes influence families' experiences of death and bereavement and vice versa;
- The family must be understood in terms of the relationships among its members, not in terms of the collection of individuals;
- A systems-thinking perspective considers how responses from family members affect each other, as well the family as a whole;
- "Grief is a family affair" – family dynamics and structure influence the meanings that family members' construe about the death and about learning to live in the world without their loved one (Nadeau, 2001, p. 95);
- A death involves not only the loss of an individual, but also a loss of "the family structure as it was" (Rycroft & Perlesz, 2001, p. 63);
- When families come together to share the grief experience, distress can be mitigated by the strengthening of relationships among family members (Walsh & McGoldrick, 1991); and,
- It is of paramount importance to care for the marital, parental and family unit in the face of bereavement (Lang et al., 2004), as well as to recognize that each type of loss has its own unique aspects.

Family members may react and grieve in different ways (Attig, 2001; Gilbert, 1996; JBI, 2006). These differences can cause discord or conflict among family members. It is often difficult for family members to understand why they can feel and behave differently even though they have all experienced the death of the same individual.

Nurses need to elicit, recognize, honour and attend to cultural and spiritual diversity, as well as family members' preferences (Lobar, Youngblut & Brooten, 2006). It is likely that nurses will encounter a myriad of diverse cultures and spiritual beliefs. It is unrealistic for the nurse to know the

Clinical Exemplar 5:

Consider the case of Paolo: After his wife Meghan's death, Paolo has found himself dealing with his own grief while also attempting to meet the emotional needs of his children, Lisa and Gwen, ages 8 and 5. Even though his wife's illness had been lengthy and he thought he had prepared himself for her death, Paolo's grief is far more intense than he had anticipated. At the same time, Lisa and Gwen need his support and understanding, and he has tried to help them, but feels inadequate for the task. Susan, a community health nurse, acknowledged Paolo's suffering and asked him if he would be open to some guidance on how to support his children. Paolo eagerly accepted Susan's offer. To counter his feeling of inadequacy, Susan pointed out that Paolo was a responsible and sensitive father as he recognized his children's needs. She mentioned that talking about his sadness and crying in front of the children may invite the children to also express their feelings which he can then validate and normalize. She also suggested that requesting help from members of his extended family to support the girls was a potentially wise decision. In addition, Susan proposed that he seek the support of his cousin with whom he has always been close, by sharing with him how things are going and how he is feeling.

nuances across customs, traditions and religions. Thus, it behoves the nurse to steer clear of stereotypes and to be aware of, and sensitive to, the diversity of responses. Please refer to RNAO's Embracing Cultural Diversity in Health Care: Developing Cultural Competence (2007) guideline, RNAO Client Centred Care (2006c) guideline, and Establishing Therapeutic Relationships guideline (2006b) for further information on recognizing the varied needs of clients. Nursing assessments should include consideration of how these aspects influence family members' relationships (Van & Meleis, 2003). Although a family's beliefs and values are influenced by the larger cultural and religious context, the family's philosophy most directly influences the perception of a stressful event (Duhamel, 2007; Wright, Watson & Bell, 1996). Even within the same cultural or religious context, families differ in their individual philosophies and responses (Boss, 2002).

Nurses may also wish to conceptualize family as the focus of bereavement care within the context of a socio-ecological perspective, which includes systems thinking (Iles & Sutherland, 2001; Lang, 2005; Marck, 2005; Shapiro, 1994). A systemic approach to caring for the bereaved “considers the impact of the death of a family member on the family as a functional unit, with far-reaching reverberations for every member and all other relationships” (Walsh & McGoldrick, 2004, p.3). Social ecology provides a framework for understanding the diverse personal and environmental factors as well as the interrelationships among these factors that influence the health of family members (Stokols, 1996) following the death of a significant other. Implicit in the socio-ecological perspective on health is the idea that the relationship between humans and their environment is reciprocal (Green, Richard & Potvin, 1996; Sallis & Owen, 1997). Humans and their environment are in dynamic relationships (Koopman & Lynch, 1999; Stokols, 1996), in addition to being in a relationship with grief. Another premise of an ecological perspective is that humans in environments can be described at several levels of aggregation: individual, family, organization, community and population (Sallis & Owen, 1997). An example of a broad approach of this concept would be to assess a couple who experience a stillbirth or an individual who experiences the loss of a parent to Alzheimer’s disease. These kinds of losses are often not socially acknowledged or recognized losses because there are frequently elements of ambiguity and disenfranchisement inherent in these situations (Boss, 2002; Doka, 1989; Lang, Fleiszer, Duhamel et al., 2011; Lang & Gottlieb, 1993). Because of this, the larger system within which the family lives, or its community and social surroundings, will impact those experiences of loss.

Clinical Exemplar 5 (cont.):

Even with his family’s help, Paolo feels that he and the girls need more help. While in the hospital, Meghan’s nurse had given him a list of resources in the area and a website on how children’s grief differs from that of adults. After one particularly trying day when his younger daughter Gwen was unusually difficult to deal with, he pulled out the list. Both Gwen and Lisa are now taking advantage of a children’s grief center in his community and are doing much better.

To further understand the challenges Paolo is undergoing as a result of his wife’s death, one can apply the socio-ecological perspective to this situation. The loss of Paolo’s wife may be minimized by friends and others. Paolo’s wife was ill for a number of years prior to her death, some family, friends and others may perceive this loss as the best outcome, a blessing for the family. These same family and friends may not fully acknowledge the loss and therefore not support the family as they need to be supported.

The creation and use of genograms and ecomaps in bereavement work is indispensable (Duhamel, 2007; Wright & Leahey, 2005). In bereavement care, these tools can be utilized according to the nurse's clinical judgment and the context of the family situation. We strongly suggest using them when nurses sense that the family might experience grief as a major challenge. These tools are very useful to initiate a conversation with the family and establish a trusting relationship with one of more family members. Families appreciate the nurses' interest in them and feel more at ease afterwards and more able to express their needs and ask questions. These tools help nurses to better understand the family context in which the grief process is evolving and to identify psychosocial factors that might have an important impact on their experiences. The family make up is a key factor to be taken into account in a global approach to nursing care. Indeed, the family structure influences the nature of each family members' unique bereavement process and the planning of their care.

Genogram

The genogram (McGoldrick & Gerson, 1985) is a diagram that represents the family internal structure. It provides rich information about relationships between family members and data about health, occupation, religion, ethnicity and migrations. The genogram allows nurses to legitimately collect data about family functioning and relevant developmental issues that help nurses with their family assessment. It is beneficial to include at least three generations. Family members are placed on horizontal rows that signify generational lines.

Ecomap

The ecomap (Levac, Wright & Leahey, 2002) is a diagram of the family's relationships with others outside the immediate family. It depicts the important connections between the family and the world. As with the genogram, the primary value of the ecomap is in its visual impact. Refer to Appendix D for instructions on how to use and construct genograms and ecomaps. Appendix D also contains a sample genogram for your review.

d) Nurses are attentive to the narratives of family members about their experiences of loss and bereavement.

Narratives are "stories" or expressions about thoughts, feelings, values, beliefs and experiences that describe our lives, bring meaning to what we live and organize information that we encounter (Gilbert, 2002; Moules & Streitberger, 1997). Attention to narratives consists of inviting family members to tell their story and actively listening to them (Harper-Chelf, Deshler, Hillman & Durazo-Arvizu, 2000; Moules & Amundson, 1997; Payne, Jarrett, Wiles & Field, 2002; Shapiro, 1994; Taylor, Amenta & Highfield, 1995; Taylor, 1997). Nichols (1995) suggests that listening to what people mean rather than to what they actually say is of fundamental importance to providing effective care.

Narratives can serve to:

- Commit the death story and bereavement experience to memory;
- Maintain a bond with the bereaved;
- Renegotiate existing relationships with others;
- Provide emotional relief and help make the experience meaningful (Dupuis & Duhamel, 2002; Gilbert, 2002; Neimeyer, Prigerson & Davies, 2002; Neimeyer, 2000);

Present the story publicly and allow other family members and significant others to share their experiences and perspectives with one another (Boss, Beaulieu, Wieling, Turner & LaCruz, 2003); and,

Provide opportunities for reassurance by the nurse.

(Dupuis & Duhamel, 2002; JBI, 2006; Sedney, Baker & Gross, 1994)

By telling their story to an attentive audience, bereaved individuals may be able to clarify their thoughts and uncover their feelings. Active, non-judgmental listening is the "greatest gift" that people who are suffering can receive (Remen, as cited in Moyers, 1993). By demonstrating a willingness to better understand, the nurse can encourage the recounting and development of a client's stories (Duhamel & Dupuis, 2004; Dupuis & Duhamel, 2002). This can help to legitimize the client's experience and to strengthen their self-worth. Encouraging family members to speak out, even if what they say may at times sound superficial and incoherent, is an intervention in itself. Indeed, it is the telling of these stories that uncovers the beliefs, values, feelings, worries and needs that are difficult for family members to express otherwise (Duhamel & Dupuis, 2003; Taylor, 1997).

Developing life stories or narratives offers an opportunity for bereaved individuals to attach meaning and gain a sense of personal control after their loss. The inherent need for meaning making is imbedded in the bereaved family members' existence, is subject to change, and is redefined as life experiences offer new information or insight. Grief is not a matter of mastering information, but rather of learning practical ways to live meaningfully again through reshaping daily life, redirecting their life story, and re-establishing connections with larger wholes of which one is a part (Attig, 2001). Evidence suggests that family members are often surprised by other members' narratives and as a result they often learn something new about each other. Sharing may assist them explore new ways of helping and supporting each other (Boss et al., 2003; Tapp, 2000). Understanding and appreciating this knowledge may reduce the sense of hopelessness that nurses often feel when faced with grief.

e) Nurses recognize that primary bereavement care is based on effective communication.

Nursing and nursing care cannot exist without relationships – with patients, families, colleagues and other health care team members. After all, nursing can be seen as a relational practice (Doane & Varcoe, 2007). A nurse has the potential to develop some of the most comprehensive relationships with patients and their families through communication. The nurse can access and impact a myriad of aspects of human experience – physical, emotional, mental, spiritual, social, cultural and political through insightful interaction. It is expected that nurses will be involved in all of these aspects.

Robinson (1996) explored some aspects of health care relationships and emphasized that “the nurse’s relational stance of curious listener, compassionate stranger, non-judgemental collaborator, and mirror for family strengths is a significant intervention that invites healing” (p. 153). Perhaps this combination of relational elements invites more than just healing. Sensitive knowledge about and attention to the power of relationships and communication endorses competent, therapeutic and collaborative nursing practice. Of most significance is that “relationships [and thus, communication] are not central to care, they are care” (Robinson, 1996, p. 153).

Important considerations in terms of communication are:

- Effective communication includes more than words – it attends to genuine presence, active listening, conveying empathy and compassion, as well as appropriate touch;
- A non-judgmental approach in working with the bereaved supports effective communication; and,
- Nurses are well situated with their ubiquitous presence across practice settings to facilitate aspects of communication and coordination between health care providers and across health and social sectors.

(Caelli et al., 2002; Duhamel, 2007; Edlich & Kübler-Ross, 1992; Hamilton, 1988; Kavanaugh & Paton, 2001; Saflund et al., 2004; Shapiro, 1994; Swanson, 1993; Wright & Leahey, 2005; Wright et al., 1996).

f) Nurses explore the family members' main concerns.

It is paramount that nurses ask about the family members' main concerns. This needs to be a deliberate nursing activity, which is distinct from assessing and attending to the needs as perceived by the nurse to be primary concerns. For example, a woman who has just lost her husband, the primary income earner, may be most concerned about her children, their reactions to their father's death, and the financial ramifications for their futures than she is about her own grief. In contrast, the nurse may have assessed that the wife's focus is on her in-laws, who are devastated by the death of their only son. As long as individuals are preoccupied by sources of anxiety, their receptivity to clinicians' interventions that target other needs is considerably decreased (Duhamel, 2007).

The following questions can help clinicians explore family members' main concerns:

- What is worrying you the most right now?
- Who do you think will be most affected by the death of your husband?
- Of all your family members, who do think will need the most support?

(Duhamel, 2007; Wright & Leahey, 2000)

g) Nurses identify, acknowledge, promote and reinforce family members' strengths and potentials.

Much of the research on bereavement has studied its negative outcomes. Focus has been on pathological grief, intense and prolonged grief reactions and marital/family breakdown. However, death and bereavement are part of the natural life cycle, and family members are equipped with inherent resources for coping with bereavement. Nurses recognize that family members carry these strengths and internal resources to help them cope and support health (Duhamel & Dupuis, 2004; Duhamel, 2007; Feeley & Gottlieb, 2000; Wright & Leahey, 2005). Nurses can promote health by helping family members draw on these internal capacities.

The concept of hardiness is particularly pertinent in bereavement (Lang et al., 2001; Lang & Carr, in press). Hardiness is similar to the term resilience, which can be described as the capacity of an individual to adjust and return to their previous state prior to a stressful situation or

event. Hardiness, however, goes beyond the concept of resilience in that it encourages an individual to recover and exceed their previous level of wellbeing prior to a stressful situation or event as a result of their experiences (Kadner, 1989; Lang et al., 2001; Patterson, 1995). Hardiness may be more or less evident depending on situation and timing. A study of bereaved parents showed that those who learned to draw on their hardiness were able to transcend not only the death of their baby, but also the countless challenges that they were subsequently compelled to face (Lang et al., 2001; Lang et al., 2004).

Bereaved family members who have learned to draw forth their hardiness may attain a sense of well-being and a higher level of health by:

- Attributing meaning to their experience (Attig, 2001);
- Changing what they believe they can, while coming to terms with what they perceive to be unchangeable; and
- Achieving self-actualization and ultimately a sense of personal growth (Lang et al., 2004).

Thus, nurses can enable family members to:

- Attain a sense of personal control through the exercise of knowledge, skill and choice of attitude;
- Have an active orientation to seek and utilize available supports (Duhamel & Dupuis, 2004), as well as a willingness to consider different strategies to cope with difficult situations; and
- Facilitate their capacity to positively reframe their situation (Feeley & Gottlieb, 2000), thus guiding them through their search for meaning in their existence following the arduous event (Lang et al., 2004).

h) Nurses provide appropriate and discerning anticipatory guidance about grief reactions and bereavement experiences.

By providing anticipatory guidance to family members, nurses can alleviate some of the distress associated with the range and diversity of physical, emotional and social reactions related to a loss. For example, a common reaction of bereaved individuals when they feel overwhelmed by grief is “I feel like I’m going crazy!” Providing reassurance about the commonality of this response can be a helpful nursing intervention.

Some other examples of key knowledge areas in primary bereavement are:

- There are variations in peoples’ reactions and emotions;
- Bereavement responses may be affected by the following (Center for the Advancement of Health, 2003, p.10):
 - ⇒ Age
 - ⇒ Developmental stage
 - ⇒ Gender
 - ⇒ History of loss
 - ⇒ History of traumatic experiences
 - ⇒ History of mental illness (i.e. depression)
 - ⇒ Type of loss
 - ⇒ Nature/quality of relationship with the deceased
 - ⇒ Familial relationships
 - ⇒ Social networks
 - ⇒ Culture and religion;
- Strong reactions may surface unexpectedly at different times;
- Beliefs about the need for resolving grief (as measured by its absence) are not often helpful to the bereaved, but rather accommodation of grief’s presence may contribute to a new relationship with the deceased over time (Meert et al., 2005; Moules et al., 2004);
- Family members often grieve in different ways – these differences can cause additional distress (Gilbert, 1996; Walsh, 2003);
- Bereaved children need individualized, developmentally -appropriate care (Becvar, 2001; Noblris & Helstrom, 2005; Shapiro, 1994);
- The bereaved have difficulty recognizing that they may need social support or professional help and are often unable to seek such resources for themselves and their

family;

- Certain situational, personal and interpersonal factors may have an impact on the risk for poor outcomes (i.e., type of loss – homicides, suicides, trauma, paediatric; or lack of available of social support) (Boss et al., 2003);
- Certain types of deaths may be stigmatized or “disenfranchised”, such as perinatal loss, suicides, military, or sudden and unexpected (Boss, 2002; Doka, 1989; Lang et al, 2011); and,
- Marital and social support are important health predictors for men and women individually, and as a couple (Lang et al., 2004).

3. Nurses ensure continuity of care for the bereaved

Continuity of care for the bereaved is not evident within the health care system. Specifically, it is not a recognized role of the nurse to identify bereaved family members and to connect them with resources. However, nurses are in the pivotal role to help navigate the system, help connect individuals and family members with resources and supports, as they traverse through health care organizations, as well as ensuring that these connections are coordinated so as to endure once they are “out of the system”.

Part of ensuring continuity of care is:

- Assessing what types of short and long-term support families might need;
- Determining what resources (internal and external) they possess; and,
- Uncovering the appropriate support resources and making the connection.

Clinical Exemplar 6:

Robert has just died after his two year battle with prostate cancer. Angela, his nurse, who has known Robert's immediate family for several months, makes a conscious effort to maintain a relationship with Robert's wife Lisa, and their two children Joseph and Samuel, after Robert's death. Prior to the family's final departure from the hospital, Angela creates time to listen and discuss options of support services with Lisa, Joseph and Samuel. She helps Lisa to connect with local funeral directors and family counselling services in her neighbourhood. She also recommends resources, such as books and videos, for Joseph and Samuel, in order to support their understanding of death and the grief process. Angela follows up with Lisa and the children a few weeks later by phone to see how they are managing and that they are receiving the services they had hoped for.

Nurses are also often positioned as the gatekeepers and liaisons to a network of support provided by other professionals. In particular, by seeking out and coordinating the supportive strengths of a variety of health care disciplines (e.g., pastoral/spiritual care, psychology, psychiatry, social work, child life, medicine, etc.), the varied needs of grieving families and family members may be better attended to. The nurse can create collaborative networks of other bereavement care team members. An example of ensuring continuity of care might entail a nurse providing a follow-up phone call to family members whose loved one was recently his/her patient (Kaunonen, Tarkka, Laippala & Paunonen-Llmonen, 2000). If the nurse is not able to carry out this kind of direct follow-up contact, it behoves her/him to ensure follow-up by a qualified individual (such as trained volunteer, family counsellor, funeral home bereavement coordinator, spiritual care worker, etc.; Van & Meleis, 2003).

Refer to Appendix F for a list of additional resources that may be useful for ensuring continuity of care

Organizations: Practice Interventions

1. Organizations value and support primary bereavement care for family members. This is reflected through creating and fostering environments that are conducive to primary bereavement care by:

- a) Ensuring appropriate resources (time, staffing, experts/teachers, physical space, funds);**
- b) Developing, implementing and sustaining primary bereavement care-centered initiatives and policies; and,**
- c) Building performance objectives.**

The foundation for providing sensitive primary bereavement care as a priority for an organization is reflected in their philosophy for holistic care across the spectrum of “prenatal to post-death”. This is about setting a tone that demonstrates a belief in the value of providing primary bereavement care to family members.

a) Ensuring appropriate resources (time, staffing, experts/teachers, physical space, funds).

An organization can operationally change its philosophy by ensuring necessary financial, human and physical resources.

Some important resource issues include:

- Appropriate staffing levels – recognizing that primary bereavement care is a core competency of nurses based on therapeutic relationships and client/family centred care and needs to be part of considerations for effective nursing care in terms of workloads, acuity/complexity of patient/family situations and assuring continuity of care;
- Physical space for private conversations with family members, for staff training and debriefing; and
- Timely access to mentors, experienced colleagues and other professionals for consultation and guidance (Kavanaugh & Paton, 2001)

b) Developing, implementing and sustaining primary bereavement care-centered initiatives and policies.

An organization must re-evaluate their primary bereavement care policies, procedures and support structures on a regular basis to ensure that the needs of families and staff are continuously being met, and that resources provided to both are based on the most up to date evidence. Commitment to primary bereavement care includes incorporating strategies to ensure uptake and sustainability of evidence-informed practice for primary bereavement care. This might include activities such as:

- Creating and promoting primary bereavement care policies and procedures;
- Integrating and highlighting primary bereavement care as an expected component of nursing practice both in orientation and during regular performance reviews; and
- Creating forums to discuss new evidence, to foster strategies to improve primary bereavement care practices, and to share practical experiences from bereaved people and those who care for them.

c) Building performance objectives.

Organizations must reflect and act on their performance with respect to providing primary bereavement care. Ideally, evaluations should consider aspects of structure, process, and outcome in order to comprehensively assess the impacts of their interventions across their system. **Please refer to Appendix ??? for suggestions for an evaluation plan.**

Clinical Exemplar 7:

“St. Teresa’s Hospital” has taken many initiatives to improve their bereavement care procedures and expectations at both staff and organizational levels. They have created a bereavement lecture series for their nurses, which includes topics such as “Immersing staff in the appropriate language needed to conduct bereavement work”, “How to proceed with follow-ups during grief work: from beginning to end of patient care”, “Up-to-date research on bereavement care”, “Bereavement resources around the community for all ages”, and “How to take care of yourself while handling bereavement work.” The hospital has also encouraged staff to have a regularly occurring interdisciplinary meeting (which includes nurses, psychiatrists, counsellors, psychologists, social workers, etc.) devoted to fostering a sense of cohesiveness when it comes to caring for families around the death of a loved one. An example of monitoring some of these initiatives is that the hospital has included in their staff performance evaluations a section on bereavement care.

2. Organizations recognize and support the nurses who provide primary bereavement care. This is reflected by:

a) Acknowledging and appreciating the nurse’s well-being as vital to successful primary bereavement care; and

b) Ensuring visible nursing leadership that establishes and maintains mechanisms to promote open conversation about primary bereavement care between nurses and other professionals as well as with all levels of management.

a) Acknowledging and appreciating the nurse’s well-being as vital to successful primary bereavement care.

Primary bereavement care, although very rewarding, can also be challenging, emotionally and physically draining, and stressful. The work pressures for nurses are clearly ever-present, requiring constant reprioritization of workloads. As such, primary bereavement care often falls to the wayside as medical and physical interventions take priority. This can affect the well-being of nurses in the sense that they are conflicted about not attending to primary

bereavement care. The persistent dissonance, from the multitude of work pressures and priorities, can contribute to compassion fatigue and nurse burnout. Organizations have a responsibility to provide opportunities for offsetting the negative repercussions on their employees. This may take the form of:

- Creating regular opportunities for debriefing, self-reflection, and mentorship;
- Providing confidential access to employee assistance programs; and
- Developing means of recognizing and promoting excellence in primary bereavement care, both for individuals and for teams.

b) Ensuring visible nursing leadership that establishes and maintains mechanisms to promote open conversation about primary bereavement care between nurses and other professionals as well as with all levels of management.

It is common for the subject of primary bereavement care to rarely enter into conversations between nurses and other professionals or managers. However, in order to truly promote successful primary bereavement care within any organization, it is essential that these discussions be brought increasingly to the forefront. Leaders or champions, at all levels, are an important link to help initiate and facilitate conversations about primary bereavement care. Some examples include:

- Creating regular opportunities for discussing primary bereavement care in meetings, clinical rounds and debriefing sessions;
- Building primary bereavement care into performance evaluation discussions; and
- Encouraging staff that have greater experience and comfort with primary bereavement care to accompany and mentor those who are less comfortable.

3. Organizations ensure continuity of care for the bereaved by building and sustaining connections and relationships with other health and human services.

Part of supporting the nurse in ensuring continuity of care is that organizations create and maintain formal relationships with community health and human service organizations which have a commitment and/or an expertise with family members around the death of a significant other. Existing inter-organizational links will make it easier for a nurse to contact an affiliated organization and advocate for continuity of care for bereaved family members.

Examples of community resources include:

- Bereavement support groups (accommodate different types of loss, different age groups, different health needs);
- Funeral homes (provide a increasing collection of resources for their communities – e.g., libraries, meeting space, bereavement coordinators, educational activities)
- Specialized counselling services (psychology, family therapy, psychiatry); and
- Online support services and websites .

These types of groups and additional services promote a network of social support as a coping resource for those who are grieving, as well as promote the family's physical health and well-being. Through the coordination and collaboration of services in the community, nurses can ensure that the bereaved receive the attention and resources that are appropriate for their needs. In this manner, nurses are making a strong effort to ensure no one "falls through the cracks".

Clinical Exemplar 8:

Dilshad's 45-year-old son, Hassan, recently died of Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease). After discussing funeral and bereavement options with the family, Gregory, the nurse following Hassan's case, realized Dilshad appeared withdrawn and inattentive. Gregory abandoned the serious conversation immediately, sensing the family needed some time to think and reflect on their own, and approached Dilshad separately. They had talked numerous times throughout Hassan's deterioration, and based on his professional nursing practice perspective, he sensed Dilshad could benefit from a supportive presence. "Would you like to go for a walk and talk Dilshad?" Gregory asked. "I would love that," she responded. After five minutes, Dilshad broke the silence. "No one knows how I feel. To watch my son suffer for so many years is heartbreaking. And now, to see him die before me is even worse. A son is supposed to outlive his mother. How am I supposed to cope with this?" she said. "You're right. This is a very hard situation," Gregory replied. "It is, isn't it? And on top of it, many people I talk to don't know much about the disease Hassan suffered from. They don't know what to say," Dilshad cried. "I have a suggestion for you Dilshad," Gregory replied. "There is this great website that I found online for individuals grieving the loss of a loved one from Lou Gehrig's disease. This online forum is a great way to preserve Hassan's story and your memories of him. As well, it will allow you to reach out beyond your physical boundaries and connect with those around the world that are suffering a similar loss. The individuals on this website may be able to offer you something more than those who don't know much about the illness and its demands on the family. "I've never heard of such a thing. I'm not very good with computers, and wouldn't know the first thing about online support," stated Dilshad in frustration. "Well, if you're willing to learn, I'm willing to show you. We can go to the hospital workroom together and I'll help you understand the site. I can even show you what else is available online if you want," said Gregory. "If you're willing to show me, I'm willing to learn. Thanks, Gregory," Dilshad replied.

4. Systems interventions for primary bereavement care can be successfully implemented where there are adequate planning strategies, resources, organizational and administrative supports and appropriate facilitation of uptake among clinicians. An effective organizational plan for implementation includes:

- An assessment of organizational readiness and barriers to implementation, taking into account local circumstances;
- Involvement of all members (whether in a direct or indirect supportive function) who will contribute to the implementation process;
- Ongoing opportunities for discussion and education to reinforce the importance of best practices;
- 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; and
- Opportunities for reflection on personal and organizational experience in implementing best practice interventions.

The RNAO (through a panel of nurses, researchers and administrators) has developed the *Toolkit: Implementation of Clinical Practice Guidelines* (RNAO, 2006d), based on available evidence, theoretical perspectives and consensus. The *Toolkit* is recommended for guiding the implementation of this *Bereavement Care Primer*. Successful implementation requires the use of a structured, systematic planning process and strong leadership from nurses who are able to transform the evidence-based interventions into policies, procedures and nursing-related practices that impact on care within the organization. The RNAO *Toolkit* (2006d) provides a structured model for implementing practice change. Please refer to Appendix G for a description of the RNAO *Toolkit: Implementation of Clinical Practice Guidelines* (2006d).

Nurse: Education and Continuing Professional Development Interventions

1. Nurses develop, nurture and evaluate an ongoing awareness of themselves in relation to bereavement and primary bereavement care, both personally and professionally.

Self-reflection and ongoing professional development are inherent to nursing practice, and are indispensable when caring for the bereaved. Engaging in self-evaluation and introspection provides the opportunity for nurses to explore and challenge their own beliefs and assumptions, and assess their strengths and struggles in primary bereavement care practice (Duhamel & Dupuis, 2003; Moules & Amundson, 1997). This reflective practice helps nurses be more aware of their own ideas, feelings, beliefs and experiences surrounding death. This can also improve their ability to provide appropriate and empathic care.

Some prompting questions to reflect on are:

- What are my fears about working with the bereaved?
- What things do I do particularly well, that I've learned from experience or evidence, that are helpful to the bereaved?
- How do I attend to the needs of family members and the relationship between them?

2. Nurses are committed to ongoing professional development of their knowledge, skills, attitudes and aptitudes in primary bereavement care.

As in other domains of nursing practice, nurses are responsible for their ongoing knowledge and skill development. In terms of primary bereavement care, this entails:

- Seeking, reading and integrating up to date evidence for practice;
- Sharing knowledge and experience with colleagues;
- Challenging selves and colleagues to strive for continuous improvement in ideas/practices around bereavement; and

- Identifying strengths and struggles in practices with the bereaved, and actively extending and addressing them.

3. Nurses should be aware of and attend to their own well-being.

Providing bereavement care can be a demanding and emotional task that may lead to nurse or compassion fatigue. It is vital that nurses stay healthy in order to be able to care for the bereaved. It is important for nurses to recognize and seek additional support for themselves (CNA, 2010).

Helping other nurses' cope with their bereavement work is additionally important. This may be done by (Cruchet, 1997):

- Offering peer support to colleagues;
- Maintaining an open atmosphere with colleagues where nurses can confide in each other ;
- Providing help to fellow nurses when they have an abundance of demands placed on them; and
- Sharing coping strategies.

Clinical Exemplar 9:

Halley, a nurse on the palliative care floor of the local hospital, was seen dragging her feet day in and day out for over two weeks by her co-worker Linda. Linda encountered Halley one day in the break room. “Have you been feeling okay lately, Halley?” Linda asked. “Well... I seem to be having a hard time picking myself up lately. I’ve taken a few extra shifts on my floor to help out with the Harvey family. They have been going through so much lately due to Mr. Harvey’s situation. I just feel so bad for the family and am doing my part to be there for them in their time of need. I don’t know why, but I seem to always be tired. I know that it will pass sooner or later,” stated Halley. Linda, looking very concerned for Halley, said, “I know that you want to help out and do as much as you can at, especially with this particular family, but you’re not superwoman! Taking care of others, especially those on the palliative care unit, is tiring emotionally and physically. As you probably know, Halley, it’s important to also take care of yourself in these circumstances in order to be helpful to others. What about going to the gym or taking an extra hour to sleep in tomorrow?” “You’re right,” Halley replied. “I feel like I’m burning out, and I could definitely use some recovery time to get over my emotional and physical fatigue. Thanks for pointing this out Linda. At times I just go, go, go, and it’s nice to have someone tell me when to slow down.”

Organizations: Education and Continuing Professional Development

1. Academic nursing programs (entry-level and advanced) include education about bereavement and primary bereavement care.

Education constitutes the teaching of theory and empirical evidence, as well as simulated and supervised practice opportunities.

- Key content areas to be included in curricula are:
- Family as the focus of care;
- Family systems and the power of relationships;
- Developing therapeutic relationships;
- Theory and current knowledge about grief and bereavement;
 - ⇒ Normal variations of grief responses
 - ⇒ Higher-risk situations for complicated grief;
- The role and the responsibility of the nurse, as constant and capable, in providing primary bereavement care;
- Nurses as well-positioned to provide primary bereavement care to families in order to help individuals heal; and
- The need for self-reflection and self-awareness around personal losses, professional experiences and bereavement.

2. Organizations include education about bereavement and primary bereavement care in all orientation and continuing nursing education initiatives, regardless of practice settings (i.e., emergency, obstetrics, medical/surgical, out-patient clinics, hospices, long-term care settings, chronic care, etc.).

Key content areas from the preceding recommendation about academic nursing programs are included in orientation and continuing nursing education opportunities. In addition to these, implementation strategies should be tailored to the various practice setting (i.e., emergency rooms, neonatology, long-term care homes and palliative care units).

This must be supported by:

- Involving experienced professionals with expert knowledge and skill in primary bereavement care in the development, implementation and evaluation of education programs for nurses; and
- Allocating resources specifically to support regular and ongoing coaching, mentoring, and supervision in simulation and clinical practice.

3. Organizations utilize the Bereavement Care Primer for Systems Change for quality and safety improvement initiatives.

Organizations utilize the primer as the foundation for:

- Developing organizational standards for primary bereavement care;
- Conducting regular employee performance reviews, that includes the nurses' self-reflection, self-evaluation and continued professional development ;
- Developing policies and procedures; and
- Developing educational sessions/programs

Health services and professional accreditation bodies utilize guidelines for:

- Developing standards to assess and evaluate organizational practices and programs in bereavement care;
- Linking to evidence-informed practice;
- Engaging clients and families in the planning of services; and
- Setting standards for student involvement/work with a practice agency or academic institution.

Nurse: Research Interventions

1. Nurses stimulate and advance research about bereavement and primary bereavement care as an integral part of their daily practice.

2. Nurse researchers who study bereavement and primary bereavement care seek opportunities to share research outcomes and new knowledge and their applicability to the practice setting. Nurse researchers also seek opportunities to listen to and learn from the voices and experiences of practicing nurses.

Research supports quality improvement, continuing competence, accountability and enhanced patient care.

The instigation and advancement of research occurs through:

- Generating questions and/or identifying knowledge gaps for investigation;
- Promoting and/or participating in studies; and
- Actively seeking to transfer, exchange and integrate appropriate and meaningful evidence into practice.

Research about grief is grounded in the common desire of multidisciplinary researchers to “give form to grief in the service of reducing pain and suffering” (Center for the Advancement of Health, 2003, p. 4).

Some examples of types of research questions to consider are:

- How do relationships affect the experience of grief?
- What is normal grief? What is abnormal grief?
- How is health impacted by grief?
- What types of interventions are most helpful in helping people deal with grief?
- How does death impact individuals of different ages or genders?

(Modified from: Center for the Advancement of Health, 2003, p. 4)

Further research is required to continue exploring “whether (and under which conditions or circumstances) bereavement interventions are indicated – or not indicated – for

individuals and families experiencing uncomplicated grief” (Center for the Advancement of Health, 2003, p.78; Schut, Stroebe, VanDenBout & Terheggen, 2001).

Research findings are then disseminated among institutions, organizations and professionals to spread new knowledge in the field of bereavement and caring for the bereaved. This can be done by submitting abstracts to conferences, writing articles for publication, sharing and discussing research with colleagues and/or by presenting at staff meetings. Additionally, less traditional knowledge translation strategies can include creating and supporting primary bereavement learning collaboratives, web-based initiatives and fact sheets. The purpose of all of these strategies is to promote knowledge exchange in bereavement care. Any action aimed to foster collaboration among interdisciplinary health care team members is essential in this domain of care.

Organizations: Research Interventions

1. Organizations assist in developing and advancing research about bereavement and primary bereavement care.

Organizations have an important role in supporting research about primary bereavement care. This occurs predominantly through:

- Valuing as leaders in institutions (managers/educators/ advanced-practice nurses) and prioritizing ongoing links between research and practice, as well as facilitating implementation of research evidence into practice;
- Generating questions and/or identifying knowledge gaps for investigation;
- Promoting and/or participating in studies and research programs;
- Supporting the transfer and exchange of research outcomes in nursing practice;
- Allocating resources (time, staffing, physical space, funds); and
- Encouraging and reinforcing nurses' and organizational involvement in research activities.

Nurses and Organizations: Policy and Community Development

1. Nurses and organizations, in partnership, advocate for recognition and promotion of evidence-informed primary bereavement care at the regional provincial/territorial and national levels.

Nurses and organizations aim to actively implement and support valuable changes in bereavement work within their community.

Some examples of engaging in advocacy are:

- Including a range of stakeholders, specifically patients and families, in all aspects of primary bereavement care initiatives;
- Promoting public discussion and education on loss, grief, bereavement and family care;
- Lobbying for a full range of adequate and effective bereavement care resources and services;
- Petitioning for consistency in funding, availability and delivery of primary bereavement care services; and
- Urging for the funding of research projects that examine primary bereavement care and the application of evidence into public policy and program development.

2. Nurses and organizations, in partnership, aim to support the health of bereaved individuals, families and communities by facilitating and promoting:

- a) **Inter-sector collaboration (i.e., between acute care, long-term care and home care, between health care organizations and non-health care organizations, etc.); and**
- b) **Inter-professional and stakeholder collaboration.**

With nurses and organizations working together to promote change, enhancements to primary bereavement care can be achieved more quickly and efficiently. These discussions can integrate the valuable opinions of all parties involved in order to provide evidence-informed care.

Some examples of interventions in this area include:

- Working with employers and other non-health care organizations to create and deliver educational campaigns on how to address bereavement situations and the potential needs of employees;
- Collaborating with other professionals and bereaved families to develop educational programs, including current knowledge, myths, stereotypes, stigma and the range of available resources, etc., for the general public (i.e., in schools, community centres, funeral homes, religious/spiritual establishments, etc.) about death and bereavement; and
- Seizing media opportunities to talk about bereavement experiences and the value of caring for bereaved family members, in light of widely publicized tragic events (e.g., 9/11, school shootings, human and/or natural disasters)

Nurse: Suggestions for Evaluation Of Systems Interventions

Organizations implementing the recommendations in this systems change primer are advised to consider how the implementation and its impact will be monitored and evaluated. The following are some possible indicators to include when designing an evaluation plan.

See table on following page.

EVIDENCE-INFORMED BEREAVEMENT CARE: PRIMER OF INTERVENTIONS TOWARDS HEALTH SYSTEMS CHANGE

A VON Canada Report: August 2012

Level of Indicator	Structure	Process	Outcome
	What you need	How you go about it	What happens
Organization	Policy, procedure and practice changes	Examine organizational culture to identify barriers and supports for an evidence-based practice culture to develop and thrive Review of existing bereavement related policies, procedures and practices	Organizational lead selected for evidence-based practice; Best practice – a standing committee agenda item; Policies, procedures and practices reflect and support best practice in primary bereavement care.
	Scheduled opportunities to discuss and evaluate primary bereavement care	Opportunities include: Bereavement included during report and shift change; Regular forums for staff debriefing; Inclusion of bereavement as a topic during team meetings, case conferences and research meetings.	Regularly scheduled opportunities allow the organization and units to incorporate discussions and evaluation of primary bereavement care into daily practice; these opportunities bring to light additional methods to improve primary bereavement care in the organization.
	Resources	Provide dedicated space for grieving families	Families have a dedicated space to grieve as well as a private area to speak to staff
	Linkages with other organizations	Develop linkages with broader community supports (funeral homes, bereavement support groups, religious institutions, etc.)	Individuals and families receive primary bereavement care beyond initial contact with health care staff; Individuals and families feel supported in their grief across the continuum.
Provider	Educational opportunities	Provide bereavement education opportunities during: Orientation sessions for new staff; Regular ongoing education sessions (didactic, interactive, and practical) for current staff. Provide presence and availability of formal and/or informal mentors/experts to coach staff in development of primary bereavement care competence	Nurse satisfaction with positive perceptions of: Increased knowledge; Increased sense of competence; Unit/organizational support for primary bereavement care. Nurse competence: Evidence of engaging in primary bereavement care with families (manager/educator/mentor-nurse perspectives); to be assessed in regular performance evaluations; Nurses report being actively involved in obtaining bereavement education; Nurses demonstrate increased confidence and comfort with providing primary bereavement care; Nurses increase involvement in evaluation and improvement activities related to primary bereavement care.
Bereaved Individual / Family	Client Satisfaction	Provide primary bereavement care to individuals and families based on their needs; Ensure families are referred to appropriate community resources and supports.	Positive reports of positive primary bereavement care experience

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Appendix A: Summary of Companion Guideline Recommendations

The best practice guidelines “Establishing Therapeutic Relationships” (2006b) and “Strengthening and Supporting Families through Expected and Unexpected Events” (2006a) are available for download from the RNAO website at www.rnao.org/bestpractices.

“Establishing Therapeutic Relationships”

Intervention 1

The nurse must acquire the necessary knowledge to participate effectively in therapeutic relationships.

- Background knowledge
- Knowledge of interpersonal and development theory
- Knowledge of diversity influences and determinants
- Knowledge of person
- Knowledge of health/illness
- Knowledge of the broad influences on health care and health care policy
- Knowledge of systems

Intervention 2

Establishment of a therapeutic relationship requires reflective practice. This concept includes the required capacities of: self-awareness, self-knowledge, empathy, awareness of ethics, boundaries and limits of the professional role.

Intervention 3

The nurse needs to understand the process of a therapeutic relationship and be able to recognize the current phase of his/her relationship with the client.

Intervention 4

All entry-level nursing programs must include in-depth learning about the therapeutic process, including both theoretical content and supervised practice.

Intervention 5

Organizations will consider the therapeutic relationship as the basis of nursing practice and, over time, will integrate a variety of professional development opportunities to support nurses in effectively developing these relationships. Opportunities must include nursing consultation, clinical supervision and coaching.

Intervention 6

Health care agencies will implement a model of care that promotes consistency of the nurse-client assignment, such as primary nursing.

Appendix A: Summary of Companion Guideline Recommendations

Intervention 7

Agencies will ensure that at minimum, 70 per cent of their nurses are working on a permanent, full-time basis.

Intervention 8

Agencies will ensure that nurses' workload is maintained at levels conducive to developing therapeutic relationships.

Intervention 9

Staffing decisions must consider client acuity, complexity level, complexity of work environment, and the availability of expert resources.

Intervention 11

Organizations will assist in advancing knowledge about therapeutic relationships by disseminating nursing research, supporting the nurse in using these findings, and supporting his/her participation in the research process.

Intervention 12

Agencies will have a highly visible nursing leadership that establishes and maintains mechanisms to promote open conversation between nurses and all levels of management, including senior management.

Intervention 13

Resources must be allocated to support clinical supervision and coaching processes to ensure that all nurses have clinical supervision and coaching on a regular basis.

Intervention 14

Organizations are encouraged to include the development of nursing best practice guidelines in their annual review of performance indicators/quality improvement, and accreditation bodies are also encouraged to incorporate nursing best practice guidelines into their standards.

Appendix A: Summary of Companion Guideline Recommendations

“Strengthening and Supporting Families through Expected and Unexpected Events”

Intervention 1

Develop an empowering partnership with families by:

- Recognizing the family’s assessment of the situation as essential;
- Acknowledging and respecting the important role of family in health care situations;
- Determining the desired degree of family involvement; and
- Negotiating the roles of both nurse and family within the partnership.

Intervention 2

Assess family in the context of the event(s) to identify whether assistance is required by the nurse to strengthen and support the family. While a family assessment should include information in the following areas, it should be tailored to address the uniqueness of each family through examining:

- Family perceptions of the event(s);
- Family structure;
- Environmental conditions; and
- Family strengths.

Intervention 3

Identify resources and supports to assist families to address the life event, whether this is expected or unexpected. Resources should be identified within the following three categories:

- Intrafamilial;
- Interfamilial; and
- Extrafamilial.

Intervention 4

Educate nurses, families, policy-makers and the public to respond to expected or unexpected life events within the family.

Intervention 5

Sustain a caring workplace environment conducive to family-centred practice by:

- Ensuring that nursing staff are oriented to the values and assessment of family-centred care;
- Ensuring that nurses have the knowledge, skill and judgement to implement family-centred care; and
- Providing ongoing opportunities for professional development for nursing staff.

Appendix A: Summary of Companion Guideline Recommendations

Intervention 6

Support the implementation of interdisciplinary family-centred practice in the workplace by:

- Ensuring appropriate resources (e.g., time, staffing);
- Developing and implementing family-centred practices and policies;
- Creating and maintaining environments that are conducive to family-centred care; and
- Developing programs that promote work life balance for employees.

Intervention 7

Advocate for changes in public policy by:

- Lobbying for public discussion on family caregiving and the development of a public position on what level of caregiving is reasonable to expect from families;
- Lobbying for public education about the value and legitimacy of the role of family caregivers and how multiple family members respond to life events;
- Lobbying for a full range of adequate and effective programs for family members who are involved in caregiving and other life events within the family;
- Lobbying for consistency in funding, availability and delivery of respite care programs and other supports for families across Ontario;
- Lobbying for the funding of research projects that examine family as the providers and recipients of care, and the application of lessons learned from this research into public policy and program development; and
- Lobbying for mechanisms within organizations for families to dialogue with one another in an open forum.

Intervention 8

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

- An assessment of organizational readiness and barriers to education;
- 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; and
- Opportunities for reflection on personal and organizational experience in implementing guidelines.

Appendix C: Definition of Terms

ANTICIPATORY GUIDANCE:

Guidance in which members of the health care team work to prepare family members for the myriad of secondary losses that they may experience following the death of a loved one (i.e., a change in the family dynamic or marital relationship, discordance between family members' reactions, loss of appetite and energy, difficulty concentrating and working, etc). This can be done by breaking the information down into smaller pieces, providing the family with the information they are prepared to handle, while concurrently inviting them to ask questions (Parkes, 1998).

BEREAVEMENT:

Bereavement refers to the objective situation or event of having lost someone significant. It can be understood as something that disrupts our lives and also as a normal human experience (de Spelder & Strickland, 2005; Stroebe et al., 2001).

PRIMARY BEREAVEMENT CARE:

“Primary bereavement care” is defined as health care professionals capturing and creating opportunities to be with, and support individuals/families in their experiences of grief and mourning surrounding the death of a loved one. These supportive practices are indicated for all bereaved individuals/family members, to differing extents (JBI, 2006), whether it is five minutes in an ER or five months in palliative care. Primary bereavement care may prevent future morbidity, and serves to direct those in need of specialized bereavement care to appropriate services. Primary bereavement care interventions and activities must be implemented at both the provider and organizational levels.

CLINICAL PRACTICE GUIDELINES OR BEST PRACTICE GUIDELINES:

Emerging guidelines, gleaned from key expert perspectives and client focus groups, and supported by the literature, on the approaches and elements of treatment that appear to result in successful treatment 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).

Ultimately, best practice guidelines are systematically developed statements to assist practitioners' and clients' decision about appropriate health care (Field & Lohr, 1990).

DISENFRANCHISED GRIEF:

Grief which is not openly acknowledged, socially validated, or publicly observed (Doka, 1989). This is often influenced by the type of death that occurs (e.g., perinatal loss, missing person, etc.).

EDUCATION RECOMMENDATIONS:

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

EVIDENCE:

Evidence is information that comes closest to the facts of a matter. The form it takes depends on context. The findings of high-quality, methodologically appropriate research provides the most accurate evidence. Because research is often incomplete and sometimes contradictory or unavailable, other kinds of information are necessary supplements to, or stand-ins for research. The evidence base for a decision is the multiple forms of evidence combined to balance rigor with expedience while privileging the former over the latter (Canadian Health Services Research Foundation, 2006).

Evidence-based learning: requires us to measure our own performance – to understand how well our learning interventions are working and build continuous cycles of improvement into our practices. After gathering and analyzing the evidence, we act on it and begin the cycle again – evaluating and analyzing.

Evidence-based practice: “the integration of knowledge of the best available research, client preferences, resources and clinical expertise when making decisions with a client about achieving the best possible health care” (College of Nurses of Ontario, 2005).

Evidence-informed practice: “... is an approach to nursing practice in which the nurse is aware of the research evidence relevant to her/his clinical practice and the strength of that evidence” (Dobbins, 2008).

Best practice: refers to “the clinical practices, treatments and interventions that result in the best possible outcomes for the patient and the health care facility providing those services” (Lippincott, Williams & Wilkins, 2007, p.1).

Promising practices: “The terms ‘lessons learned,’ ‘good practices’ and ‘promising practices’ are all terms used to describe useful practices. These terms are often used to indicate practices or approaches that have not been evaluated as rigorously as ‘best practices,’ but that still offer ideas about what works best in a given situation” (Information & Knowledge for Optimal Health, 2007) – often reported by experts in the field as beneficial (Walker & Bruns, 2006).

FAMILY:

Being unique and whomever the person defines as being family. Family members can include, but are not limited to parents, children, siblings, neighbours and significant people in the community .

GRIEF:

Grief is defined as the complex emotional, cognitive and perceptual responses to loss. It encompasses a diverse psychological, physical and spiritual set of manifestations. It is highly variable and assumes a wide variety of expressions and trajectories which can be shaped by the kind and intensity of the experienced losses (Corless, Germino & Pittman, 2003; de Spelder & Strickland, 2005; Stroebe et al., 2001).

HARDINESS:

A personal resource characterized by a sense of personal control over the outcome of life events and hardships such as the death of a fetus/infant, an active orientation toward meeting the challenges brought on by the loss, and a belief in the ability to make sense of one’s own existence following such a tragedy” (Lang et al., 2001, p. 502)

LARGER SYSTEM:

Can refer to people and organizations outside the family (e.g., community organizations, support groups, neighbours, co-workers).

MOURNING:

Mourning is “the process by which a bereaved person

integrates the loss into his or her ongoing life.” (de Spelder & Strickland, 2005, p. 269). This concept is closely related to grief. Mourning considers “the social expressions or acts expressive of grief that are shaped by the practices of a given society or cultural group” (Stroebe et al., 2001, p.6).

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.

PATIENT/CLIENT- OR FAMILY-CENTERED CARE:

An approach in which clients are viewed as whole persons; it is not merely about delivering services where the client is located. Client-centred care involves advocacy, empowerment, and respecting the client’s autonomy, voice, self-determination and participation in decision- making (RNAO, 2006c). Care also incorporates the client’s family needs and the relationship between the family dynamics and the client’s health condition.

PRACTICE RECOMMENDATIONS:

Statements of best practice directed at the practice of health care professionals that are evidence-informed .

RELATIONSHIPS:

A state of connectedness between people. It may refer to kinship, emotional connection, romantic involvement, friendship or other.

RESEARCH RECOMMENDATIONS:

Statements of research intent directed at the development of best practices for health care professionals.

RESILIENCE:

The ability of an individual to bounce back from a stressful life occurrence and return to their previous state before the stressor.

RESOURCES (INTERNAL, EXTERNAL, INTRAFAMILIAL, INTERFAMILIAL, EXTRAFAMILIAL):

Resources, both internal (i.e., personal resources) as well as external (i.e., external to the person), are potential “individual/personal and collective strengths”. They may be characteristics, traits, competencies, or means of a person, family, or community.

Inter-familial resources: Those resources that exist or occur among or involving several families. These resources can be in the form of support groups unique to the family’s needs, newsletters, organized education programs related to specific skills training, and family or friends to help with housekeeping, dietary needs, transportation and companionship (RNAO, 2006a).

Intra-familial resources: Those resources that exist or occur within the family. Nurses can support families in recognizing their strengths and building upon them; in times of stress each family copes in their unique way. During assessments, individuals’ coping mechanism should be identified such as spirituality, individual counselling, cultural strengths, and implementing self-care strategies (RNAO, 2006a).

SOCIAL ECOLOGY:

The study of the relationships between individuals, social groups and their environments.

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 the change or solution to the problem. Stakeholders can be of various types, and can be divided into opponents, supporters and neutrals (Ontario Public Health Association, 1996).

THERAPEUTIC RELATIONSHIP:

The therapeutic relationship is grounded in an interpersonal process that occurs between the nurse and the client(s). Therapeutic relationship is a purposeful, goal directed relationship that is aimed at advancing the best interest and outcome of the client (RNAO, 2006b).

Appendix E: Pocket Acronym Reference Guide

Remember to always:

Validate (this is happening)
Normalize (this is normal)
Legitimize (this is an OK way to feel or these feelings are justifiable)

Acronym: *FAMILIES are our priority*

F - Focus on the family
A - Acknowledge and validate the death
M - Manage main concerns
I - Identify strengths and potentials
L - Listen to their story
I - Initiate links to potential resources
E - Engage in an emotionally and authentically present way
S - Support grief reactions and bereavement experiences

Français – *FAMILLES sont nos priorités*

Focaliser sur les membres de la famille
Accepter et reconnaître la mort
Miser sur leurs principales préoccupations
Identifier leurs forces et potentiel
Leur histoire est importante. Les écouter
Lier la famille aux ressources disponibles
Engager d'une manière authentique et compatissante
Soutenir les réactions et expériences de la mort

Appendix F: Educational Resources

The following educational resources have been compiled by the development panel as a resource for nurses and their clients in learning more about bereavement care. It is not intended to be an inclusive listing.

Journal Articles and Links:

Brown, I. (2003, Spring). What are the causes of these psychological problems? *In Touch*, 26 (11-12). Retrieved March 5, 2010 from <http://www.niichro.com/2004/pdf/INTouch/in-touch-vol-26.pdf>.

Canadian Hospice Palliative Care Association. (2007, March 29). *Moving forward by building on strengths: A discussion document on Aboriginal hospice palliative care in Canada*. Retrieved March 5, 2010 from http://www.chpca.net/interest_groups/aboriginal_issues/AHPC_Final_Paper_March_29_2007_English.pdf.

Castellano, M. B. (2002). Aboriginal family trends: Extended families, nuclear families, families of the heart. Retrieved March 5, 2010 from <http://www.vifamily.ca/library/cft/aboriginal.html>.

Department of National Defence. (2009, September 1). Religions in Canada Native Spirituality. Retrieved March 5, 2010 from <http://www.cmp-cpm.forces.gc.ca/pub/rc/rel/ns-sa-eng.asp>.

Flexhaug, M. & Yazganoglu, E. (2008, April 10). Best and promising practices in suicide bereavement support services: A review of the literature. Retrieved March 5, 2010 from <http://www.amhb.ab.ca/Initiatives/suicidePrevention/Documents/Best%20and%20Promising%20Practices%20in%20Suicide%20Bereavement%20Support%20Services%20-%20A%20Review%20of%20the%20Literature.pdf>.

Lang, A., Goulet, C., & Amsel, R. (2003). Lang and Goulet Hardiness Scale: Development and testing on Bereaved Parents Following the Death of their Fetus/infant. *Death Studies*, 27(10), 851-880.

Public Health Agency of Canada. (2009, November 26). Family violence in Aboriginal communities: An Aboriginal perspective. Retrieved March 5, 2010 from <http://www.phac-aspc.gc.ca/ncfv-cnivf/publications/fvabor-Eng.php>.

Puchalski, C., Ferrell, B., Virani, R., Otis-Green, S., Baird, P., Bull, J., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: The report of the consensus conference. *Journal of Palliative Medicine*, 12(10), 885-904.

Royal Canadian Mounted Police. (n.d.). *Native spirituality guide*. Retrieved March 5, 2010 from <http://www.rcmp-grc.gc.ca/pubs/abo-aut/spirit-spiritualite-eng.htm>.

Smylie, J. (2000). A guide for health professionals working with Aboriginal peoples: The sociocultural context of Aboriginal peoples in Canada [Electronic version]. *Journal of Obstetrics and Gynaecology of Canada*, 100, 1-12. Retrieved March 5, 2010 from <http://www.sogc.org/guidelines/public/100E-PS2-December2000.pdf>.

Smylie, J. (2001). A guide for health professionals working with Aboriginal peoples: Health issues affecting Aboriginal peoples [Electronic version]. *Journal of Obstetrics and Gynaecology of Canada*, 100, 1-15. Retrieved March 5, 2010 from <http://www.sogc.org/guidelines/public/100E-PS3-January2001.pdf>.

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Thorson, J. A. (1985). A funny thing happened on the way to the morgue: Some thoughts on humor and death, and a taxonomy of the humor associated with death. *Death Studies*, 9(3), 201-216.

Wheeler-Roy, S., & Amyot, B. A. (2004). *Grief Counseling Resource Guide: A Field Manual*. New York State office of Mental Health. <http://www.omh.state.ny.us/omhweb/grief/>

Websites:

Site for Health Management
<http://www.mayoclinic.com/>

Palliative Care in Edmonton Alberta
<http://www.palliative.org/>

Information and support on palliative and end-of-life care, loss and grief
<http://www.virtualhospice.ca>

To enhance the quality of life for those facing advancing illness, death and bereavement <http://www.victoriahospice.org/>

To help improve the health and quality of life of the population
<http://www.fraserhealth.ca/>

Information on death-related grief for the community and professionals.
<http://grieflink.org.au/>

For those with mental health issues who are dying
<http://www.promotingexcellence.org/mentalillness/>

For perinatal loss
<http://www.yorku.ca/hlln/continuing-education-tools.html>

Hospice Programs
http://www.hospice.on.ca/member_programs.php

Books:

Buscaglia L. (1982). *The fall of Freddie the leaf. A story of life for all ages*. New York, NY: Henry Holt & Company.

Kuhl, D. (2002). *What dying people want: Practical wisdom for the end of life*. 1st ed. New York, NY: PublicAffairs.

Kushner, H. S. (1981). *When bad things happen to good people*. New York, NewYork: Schocken Books, Inc.

Rupp, J. (1988). *Praying our good-byes*. New York: Ballantine Books.

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van Bommel, H.(1986). *Family Hospice Care: Pre-planning and Care Guide*. Scarborough, ON: Legacies Inc.

Wylie, B.J. (1997). *Beginnings: A Book for widows*. (4 ed).Toronto: McClelland &Stewart.

Related RNAO Best Practice Guidelines:

Registered Nurses' Association of Ontario. Healthy Work Environments Best Practice Guidelines
<http://www.rnao.org/Page.asp?PageID=751&SiteNodeID=241>

Registered Nurses' Association of Ontario. (2006). *Client Centred Care*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=924&ContentID=798>

Registered Nurses' Association of Ontario. (2006). *Collaborative Practice Among Nursing Teams*. Toronto, ON: Author.
http://www.rnao.org/Page.asp?PageID=122&ContentID=1202&SiteNodeID=241&BL_ExpandID=

Registered Nurses' Association of Ontario. (2006). *Establishing Therapeutic Relationships*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=924&ContentID=801>

Registered Nurses' Association of Ontario. (2006). *Supporting and Strengthening Families Through Expected And Unexpected Life Events*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=924&ContentID=819>

Registered Nurses' Association of Ontario. (2002). *Toolkit: Implementation of Clinical Practice Guidelines*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=924&ContentID=823>

Registered Nurses' Association of Ontario. (2007). *Embracing Cultural Diversity in Health Care: Developing Cultural Competence*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=122&ContentID=1200>

Registered Nurses' Association of Ontario. (2011). *End-of-Life Care During the Last Days and Hours*. Toronto, ON: Author.
<http://www.rnao.org/Page.asp?PageID=924&ContentID=3592>

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Appendix G: Stakeholder Acknowledgement

Stakeholders representing diverse perspectives were solicited for their feedback. The Research Team wish to acknowledge the following individuals for their contribution in reviewing this Bereavement Care Primer for Systems Change:

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