

**Preparedness of Manitoba Palliative Care Nurses to Practice
Using Canadian Hospice Palliative Care Nursing Standards**

By

Darlene Grantham RN, BN

**A Practicum Project
Submitted to the Faculty of Graduate Studies in Partial
Fulfillment of the Requirement for the Degree of**

Master of Nursing

**Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba**

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FACULTY OF GRADUATE STUDIES

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Abstract

Individuals who choose nursing as a career will care for a person with a terminal diagnosis and be expected to support the family through the process of dying and the event of death. Nurses provide more care to dying persons and their families than any other healthcare professional and quality end-of-life care depends on a well-prepared nursing profession (Ferrell, Virani, & Grant; 1999; Pimple, Schmidt, & Tidwell, 2003). As the demand for specialty palliative care services increases so will the educational needs of front-line palliative care nurses.

In Canada, palliative care nurses are concerned about standards of practice and educational preparation to meet their needs (Kristjanson & Balneaves, 1995). The Canadian Nurses Association's (1998) Policy Statement on Educational Support for Competent Nursing Practice encourages nurses to use professional standards in their area of practice on a continuing basis in order to practice safely and competently. The Canadian Hospice Palliative Care Association (2002) Nursing Standards Committee developed standards of practice and circulated them across Canada to nursing stakeholders. To date, Manitoba nursing educators have not been given clear direction on how to implement the Canadian Hospice Palliative Care Association (CHPCA) Nursing Standards of Practice.

The interrelationship between continuing education, clinical competence and palliative care practice is complex and needs to be handled in an education format that is conducive to front-line palliative care nurses' needs. The purpose of this practicum project was to conduct a continuing education needs assessment survey of Manitoba front-line palliative care nurses based on the CHPCA Nursing Standards of Practice. A

review of the literature contributed to the identification of four summary statements that articulate the need for palliative care nurses to incorporate the CHPCA Nursing Standards into their practice.

Many of the nurses who responded to this survey gave feedback that raised specific areas of practice challenges and pointed out priority education needs. The data were used to develop a palliative care nursing continuing education guideline. It is hoped that palliative care nursing educators will use this guideline in their program planning to ensure that palliative care nurses are well-prepared when caring for terminally ill persons and their families.

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Chapter One

Statement of the Problem

Compassionate and competent care that is directed at improving the quality of life for individuals and their families with a terminal illness is interdisciplinary in nature and occurs in a variety of settings including home, acute care, long-term care facilities and hospice (Adriaansen & Frederiks, 2002). Consequently, individuals who enter the nursing profession will, at some time in their career, assist a person and their family through the dying process or be present during the event of death. In fact, nurses provide more care to dying persons and their families than any other healthcare professional and quality end-of-life care is dependent on a well-prepared nursing profession (Ferrell, Virani, & Grant, 1999; Pimple, Schmidt, & Tidwell, 2003).

Unfortunately, despite increased recognition of the importance of palliative care such content has been neglected in most nursing education programs (Dowell, 2002; Ersek, Kraybill, & Hansberry, 1999; Ferrell et al., 1999; Raudonis, Kyba, & Kinsey, 2002; Simpson, 2003). In Manitoba, palliative care is taught primarily to students who are registered in undergraduate programs in established education facilities (Ross, McDonald, & McGuinness, 1996).

Kristjanson and Balneaves (1995) surveyed 100 Canadian palliative care nurses in order to obtain information about their perceptions of practice and professional issues. Two main issues of concern were common within this group. First, standards of practice for palliative care nursing had to be developed and, second, the educational needs of palliative care nurses had to be addressed. In 2002, the Canadian Hospice Palliative Care Association (CHPCA) Nursing Standards Committee developed palliative care nursing

standards of practice and circulated them across Canada to various stakeholders. It is the goal of the CHPCA Nursing Standards Committee that every palliative care nurse incorporates all the CHPCA Nursing Standards of Practice into their practice. It is only then that a standard of palliative care nursing practice will be defined and care will be delivered in a consistent manner to all Canadians who are living with and dying from advanced illness. In order for the Standards of Practice to be implemented, it is necessary that palliative care nurses at the front-line be educated to use these standards. In Manitoba, no formal education plans have been developed to prepare nurses to incorporate the CHPCA Nursing Standards of Practice into their clinical practice.

Significance of the Problem

As the demand for specialty palliative care services increases so will the educational needs of nurses working in this field (James & MacLeod, 1993; Lloyd-Williams & Field, 2002; Meraviglia, McGuire, & Chesley, 2003; Raudonis et al., 2002; White, Coyne, & Patel, 2001). Growth in palliative care knowledge is creating a complex theory base that is producing significant gaps between palliative care nursing education and palliative care nursing practice (Dowell, 2002; Jodrell, 2001; Rosser, 1997). Degner, Gow, and Thompson (1991) found in their Canadian study that failure to link education to nursing practice has been a major limitation of nursing knowledge in the area of palliative care. As a result, there is evidence that nurses who provide palliative care services to terminally ill persons and their families experience difficulties in providing appropriate care to those who are dying (Ferrell et al., 1999; Ferrell, Virani, Grant, & Jurez, 2000; Hopkinson, 2001; Kristjanson & Balneaves, 1995; Patterson, Molloy,

Jubelius, Guyatt, & Bedard, 1997; The Support Principle Investigators, 1995; White et al., 2001; Wilke, Judge, Wells, & Berkley, 2001).

Loftus and Thompson (2002) found evidence that palliative care education has a strong link to increased clinical effectiveness. Nurses working in palliative care settings have cited how palliative care education has benefited their clinical practice and improved their overall general knowledge base in palliative care issues (Kenny, 2003; Kristjanson & Balneaves, 1995; Manias, Kristjanson, & Bush, 1997; Matzo, Sherman, Mazanec, Virani, & McLaughlin, 2002; Rosser, 1997). Improving the quality of care given to persons and their families can only be achieved by having well trained nurses with adequate educational resources and support (Dowell, 2002). White et al. (2001) strongly suggest that identifying nurses' educational needs is the first step toward changing practice.

Recent advances in palliative care knowledge have led to the development of palliative care as a nursing specialty. The Canadian Nurses Association (CNA) has now accepted Hospice Palliative Care Nursing as the twelfth specialty area in nursing. Esper, Lockhart, and Murphy (2002) stress the importance of the nursing specialty certification examination process because this has a direct influence on nursing education as well as a significant impact on nursing practice. Until recently, standards of practice had not been developed for palliative care nursing (CHPCA, 2002). Therefore guidelines did not exist for continuing educators to use when preparing for palliative care program development (CHPCA, 1995). Gearing educational programs to better meet the needs of Manitoba palliative care nurses will help to increase their palliative care knowledge base and close gaps that exist between their education needs and nursing practice.

Purpose of the Practicum

The purpose of this practicum was to conduct a continuing education needs assessment of palliative care nurses in the Province of Manitoba by distributing a survey that was based on the CHPCA Nursing Standards of Practice. Feedback from palliative care nurses was then used to develop a palliative care nursing education guideline for continuing educators to use when doing program development for palliative care nursing practice. Therefore only continuing nursing education needs were explored in this practicum.

Summary Statements Derived from the Literature

This practicum project was based on summary statements that were derived from review of the literature that articulate the need for palliative care nurses to implement CHPCA standards into their practice in order to be well-prepared to care for terminally ill persons and their families. They are as follows:

1. Gaps exist between palliative care nursing education and nursing practice.
2. The nurse's role at the bedside of a dying person can have a profound effect on the quality of life of the dying and the bereaved.
3. Nursing standards of practice set boundaries and act as a guiding force for hospice palliative care nursing practice and education.
4. Responding to nurses' learning needs in ways that are relevant to them is the most effective way of facilitating change in their practice.

Definition of Terms

Palliative care. As defined by the World Health Organization (WHO) (2003):

Palliative care is an approach that improves the quality of life of persons and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications. (p. 1)

The World Health Organization's (2003) definition of Palliative Care for Children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows:

The principles apply to other pediatric chronic disorders:

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes. (p. 1).

End-of-life care. Palliative care and end-of-life care are often used interchangeably. For the purposes of this practicum palliative care and end-of-life care will be used interchangeably.

Palliative care nursing. The essence of palliative care nursing is the art and science of caring for and comforting the dying and their families (Vachon as cited in Ferrell & Coyle, 2001). This definition is widely accepted.

Manitoba palliative care nurse. For the purpose of this study this term will refer to any nurse who has designated palliative care as their area of work on their College of Registered Nurses of Manitoba registration form.

Continuous nursing education. Continuous nursing education consists of learning experiences based on first level nursing preparation and practice and is organized by a facility, agency, or educational institution undertaken by a nurse to enhance his/her nursing competencies (Canadian Nurses Association, 1998).

CHPCA Nursing Standards of Practice. The CHPCA Nursing Standards of Practice are based on six dimensions of Davies and Oberle's (1990) Supportive Care Framework and reflective of the CHPCA (2002) Norms of Practice. The purpose of the nursing standards is to define the standard of nursing care that can be expected by all Canadians who are living with and dying from advanced illness and at the same time establish requisite knowledge for nurses. This document supports ongoing development of hospice palliative care nursing and promotes palliative care nursing as a specialty.

Summary

Until recently, Canadian standards of practice had not been developed to guide the education of palliative care nurses. The CHPCA Nursing Standards of Practice have now been disseminated to various educational stakeholders across the country. Yet it was not known whether Manitoba palliative care nurses felt prepared to practice using these standards and no formal implementation plan had been developed. This practicum project has contributed to the implementation phase of the CHPCA Nursing Standards of Practice by providing a palliative care nursing continuing education guideline based on an assessment of the continuing education needs of Manitoba palliative care nurses.

Chapter Two

Literature Review

The most unique feature of palliative care nursing is the constant proximity to death and dying. It is this that gives rise to the majority of problems that nurses face (Webber, 1994). Despite published research and knowledge that has focused on death and dying in the last 10 years, nurses who care for dying persons are still voicing their distress of not being capable of meeting this population's needs (Benoliel, 1998; Esper et al., 2002; Webber, 1994; Wilkie et al., 2001). Benoliel (1998) reported that nurses face challenges in clinical practice where death is a critical feature because they have not been well educated in the area of palliative care.

Based on a comprehensive literature review, there was very little empirical evidence to help identify the continuing educational needs of palliative care nurses. In fact review of the literature, including the domains of nursing, sociology and psychology, revealed only six palliative continuing educational needs assessments. Of these studies, only one looked solely at the continuing educational needs of front-line palliative care nurses (Raudonis et al., 2002), whereas the others focused on the educational needs of all healthcare professionals (i.e., physicians, nurses, healthcare aides).

Palliative care nurses with two years experience are now eligible to write the Canadian Hospice Palliative Care Nursing Certification Exam. This exam is reflective of current CHPCA Nursing Standards of Practice (CHPCA, 2002). Eleven nurses from across Canada came together in April, 2001 to draft the first set of palliative care nursing standards and, in the summer of 2001, circulated the draft standards (French and English) to nurses across the country for critique and feedback. Based on the comments received

from 180 nurses the standards were revised and presented at the Canadian Hospice Palliative Care Association Nursing Group Meeting held October, 2001, in Victoria, BC. At this meeting, 300 palliative care nurses (90.5%) approved the CHPCA Nursing Standards of Practice. By being well informed of the standards and through an evidence-based continuing educational process, palliative care nurses can be successful in writing the national certification exam.

This literature review will highlight the state of knowledge relative to the educational needs of palliative care nurses, and explore the challenges palliative educators face when attempting to provide continuing educational sessions to front-line nurses.

Need for Palliative Care Nursing Education

Palliative care is a holistic interdisciplinary approach taken to care for terminally ill persons and their families that addresses their physical, psychosocial, spiritual and emotional needs in a variety of settings (Ferrell, Virani, Grant, & Rhome, 2000). Although palliative care is interdisciplinary (Sheehan & Ferrell, 2001), it is nurses who are in the unique position to make substantial changes to end-of-life because they spend more time with dying persons and their families than any other team member (Sherman, Matzo, Rogers, McLaughlin, & Virani, 2002). It is within these areas and various settings that even the most competent nurse can be challenged. In Sellick, Charles, Dagsvik, and Kelley's (1996) study of healthcare providers (physicians, nurses, healthcare aides) from multiple settings, it was felt that current palliative care education was fragmented, general and too basic to ensure quality person and family care. These researchers argued that due to the rapid development of palliative care service provision, a huge gap in information

existed between what is known and what is being practiced and the palliative care providers that were interviewed in their study placed education as a primary concern. Similar findings were also reported by Dowell (2002) who found nurses, who help terminally ill persons die, are expected to make complex assessments and communicate their findings to an interdisciplinary team and they have not been trained to do so.

Davies and Oberle's (1990) work used research findings to define the knowledge base and core competencies needed by practicing palliative care nurses. White et al. (2001) asked practicing oncology nurses if they felt adequately prepared for end-of-life care in order to determine core competencies and educational needs. How to talk to patients and families about dying was the top rated core competency consistent among these nurses. Also pain control and comfort care were also frequently selected by nurses as important end-of-life issues. Communicating about end-of-life issues, pain control and comfort care are core competency areas described in Davies & Oberle's (1990) work. In addition Ersek et al. (1999) showed serious deficits in nurses' knowledge of pain control and other symptom management issues (competencies also recognized in Davies and Oberle's work). These clinicians felt their previous education neglected to prepare them to adequately incorporate these competencies into their practice (Ersek et al., 1999).

Palliative Care Nursing Educational Needs

To ensure the needs of practicing nurses are met, information about the continuing educational needs of experienced practitioners must be collected and analyzed prior to the development and implementation of any curriculum. Jeffrey (1994) conducted a needs assessment survey in Worcester, UK to determine the views of general practitioners and community hospital nurses about their present level of knowledge and

future educational needs in palliative care. In total, 134 questionnaires were distributed to general practitioners and 137 to community nurses. In addition, 122 questionnaires were sent to nursing staff at three community hospitals. The response rate was 72% with a total of 193 nurses responding. The respondents in this qualitative evaluation were considered an experienced group. For this group of professionals, pain, symptom control and bereavement care were determined to be the priority foci for continuing education. All respondents felt they lacked protected learning time to attend continuing educational sessions and 95% of nurses thought interdisciplinary educational sessions would be beneficial.

Two years later, Sellick et al. (1996) conducted an educational needs assessment in order to help guide the development of a regional program in Eastern Canada. This survey went to 146 healthcare providers (nurses, nursing assistants, social workers, palliative care coordinators, chaplains, volunteers and administrative staff) from multiple settings and 135 surveys were returned. Two main areas were identified for program planning. First, a knowledge deficit existed in the areas of pain and symptom control and difficulty communicating end-of-life issues. Second, there appeared to be a lack of attention to the education needs of palliative care providers. Once again the problem of time was cited as a barrier to continuing educational learning. Respondents recommended that manageable caseloads be considered so professionals could be allowed the time to attend continuing educational sessions.

Another Canadian study in Victoria, BC distributed over 2,000 questionnaires to practicing physicians and nurses. The survey response rate was 365 (18%): 102 were physicians and 263 by registered nurses. Both physicians and nurses indicated that they

felt comfortable most of the time caring for dying persons and their families but reported a number of priority educational needs including pain, symptom management, family support and communication skills, especially when ethical issues were involved (Samaroo, 1996). Interestingly, physicians rated pain and symptom control as the top priority educational need, while registered nurses expressed family support as their first priority. This illustrates that palliative care is interdisciplinary but educational needs differ between disciplines. However, all respondents agreed that education must focus on physical comfort first because a patient must be physically comfortable before emotional, spiritual and psychosocial support can be facilitated.

Also Patterson et al. (1997) conducted an educational needs assessment in Ontario by surveying three nursing homes. Broad headings were used in the questionnaire, e.g. staff stress management. Questionnaires were distributed to 415 healthcare providers. The response rate was 54% and respondents agreed continuing education was needed to increase their competence. Stress management was the priority educational need identified by palliative care providers as well as pain and symptom management. Additionally the respondents in this needs assessment concluded that the primary factor influencing attendance at a palliative care workshop was loss of pay, time and the location of the workshop.

Ersek et al. (1999) conducted a similar study in two nursing homes in the United States. The purpose of their study was to explore and describe the educational needs and concerns of licensed nursing staff (RNs and LPNs) and certified nursing assistants. Focus group interviews were conducted in both nursing homes. A total of 15 licensed staff and 39 certified nursing staff participated in the study. Major concerns of these nursing home

staff were symptom management, communication and interactions with physicians. Although both groups described similar themes, specific issues within each topic were different for them. For nurses, symptom management issues focused around lack of knowledge and skills regarding assessing and managing pain in cognitively impaired clients, use of adjuvant pain medication, alternative routes for pain medication and complex pain management regimes. Nurses were also concerned about fears of addiction, working with physicians who lack expertise in pain management at end-of-life, and fear of administering the last dose. Nurses also felt frustrated when communicating and interacting with physicians. This frustration stemmed from the fact that most physicians were unwilling to consider their assessment and recommendations. Respondents found communication skills as a central educational need. Also nurses commented that finding time to provide high quality, compassionate care was a major struggle and respondents were often distressed over the amount of time they could actually spend with dying persons.

Raudonis et al. (2002) were the only researchers who looked solely at the educational needs of nurses. They studied 164 licensed nurses from 24 long term care facilities in Texas and found deficiencies in their knowledge of palliative care. Lack of knowledge was tested by administering the Palliative Care Quiz for Nursing. This 20 item questionnaire consists of three content areas; philosophy and principle of palliative care, pain and symptom management, and psychosocial aspects of care. The results from the Palliative Care Quiz for Nursing used in this study suggest that nurses employed in long term care need more education on pain and symptom management as well as the philosophy and principles of palliative care.

When comparing the above six studies, many of the respondents felt they had not been adequately trained in their undergraduate programs or basic training to care for the dying and their families (Ersek et al., 1999; Jeffrey, 1994; Patterson et al., 1997; Samaroo, 1996). The main educational needs continuously cited in the above studies were pain and symptom control as well as communication skills. Pain and symptom control were linked to comfort care interventions and palliative treatments. Communication difficulties focused around time constraints and the inherent problems of interdisciplinary teamwork. Lack of time to care for terminally ill persons and their families seemed to increase both stress and distress for healthcare providers and time was also seen as a barrier for attending continuing education sessions. A consensus among respondents that was noted was the request for interdisciplinary learning sessions.

Education Challenges

The interrelationship between continuing education, clinical competence and the quality of palliative practice is complex and needs to be handled in an education format conducive to the working nurse. Education requires funding and a well thought out educational method with an appropriate evaluation component in order to meet particular practitioner's needs and service requirements. Ferrell (1998) conducted a descriptive survey consisting of 1,848 questionnaires that were distributed to palliative care providers throughout metropolitan and rural areas of Australia. Results of this extensive endeavor showed that palliative care providers felt travel, distance and cost were the reason why present educational and training sessions were not well attended. In addition, it was felt that palliative care education activities had rapidly expanded in the last 10 years but training and education had failed to establish qualified palliative teaching staff in this

field. Most importantly, this researcher highlighted that in order to ensure that the education is effective and appropriate more evaluation initiatives had to be undertaken. Past research has focused on how education and training should be provided but has failed to show what education and training programming would improve the quality of patient care.

Summary

The literature highlights the importance of palliative care continuing education program development that must be geared to front-line palliative care providers, while also identifying the various gaps that exist between their education and practice. It appears this gap has developed due to the rapid development of palliative care knowledge without additional educational support. Most of the research studies are based on feedback from interdisciplinary team members. In order to address the educational needs of nurses, who provide the majority of care to terminally ill patients and their families, it is essential to conduct a needs assessment of this group. Identifying palliative care nurses educational needs is the first step to changing practice and improving the care outcome for terminally ill persons and their family.

Chapter Three

Methodology

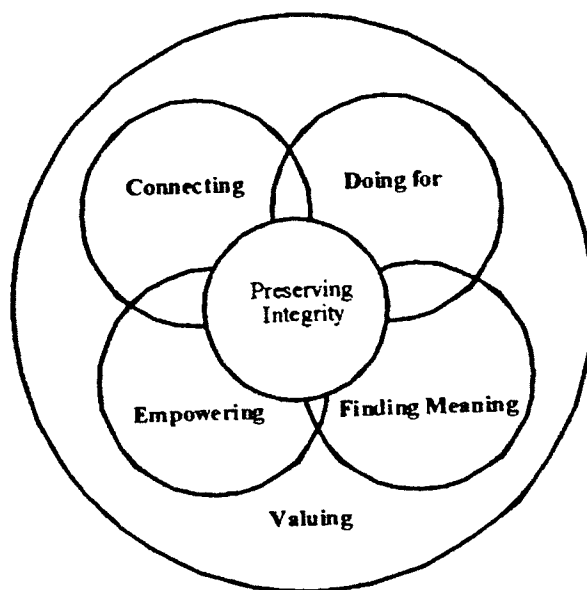
The research methodology used in this practicum project was a needs assessment survey. Polit and Hungler (1995) believe a needs assessment represents an effort to provide a decision maker with information for action. Palliative care continuing nursing educators need information for action. Dillman (1999) stresses the importance of the actual sample reflecting each unit of the population and that there is an equal opportunity of each unit to be included. The College of Registered Nurses of Manitoba (CRNM) has a record of all nurses in the Province of Manitoba who designate themselves as palliative care nurses. Therefore, all nurses in Manitoba who designated themselves as palliative care nurses had an equal opportunity to complete the survey. This sample of palliative care nurses reflected the population in Manitoba. The feedback from this survey reflected what educational preparation was needed to support palliative care nurses in the Province of Manitoba in order for them to practice using the CHPCA Nursing Standards of Practice. The feedback was also used to develop a guideline for the continuing education of palliative care nurses as they strive to practice within national standards.

Canadian Hospice Palliative Care Association Nursing Standards of Practice

Standards of Practice define and set boundaries that act as a guiding force for practice and education in the nursing specialty area and are supported by evidence-based research (Esper et al., 2002). The Canadian Nurses Association's (1998) Policy Statement on Educational Support for Competent Nursing Practice encourages nurses to use professional standards in their area of practice in order to practice safely and competently. Davies and Oberle's (1990) Supportive Care Model used research findings

to define the knowledge base and competencies of palliative care nursing (Dunniece & Slevin, 2002; Larkin, 1998; Reimer, Davies, & Martens, 1991). This model was adopted as the framework for hospice palliative care nursing and is the foundation of the CHPCA Nursing Standards of Practice which guided this practicum project and provided a guideline for discussion of the findings.

Figure 1. Supportive role of the nurse in palliative care-dimensions of care.



Dimensions of the Framework

Valuing. The attitude of *Valuing* provides the context within which the nurse's activities take place and therefore is considered the foundation for all nursing activities. Two components are involved in *Valuing*: global and particular. Global valuing means to have utmost respect and an inherent worth of all humans. Particular valuing is more individualized and refers to the nurse's respect and acceptance for the unique characteristics and abilities of the person. Nurses must understand their own valuing in order to bring a balance between their personal qualities and nursing activities.

Preserving Integrity. *Preserving Integrity* is the maintenance of personal wholeness of both person and nurse. It is the core of the model and is integral to the nurse's effective functioning. The nurse must be able to maintain a sense of wholeness, self-worth and self-esteem by recognizing his/her own personal behaviors and needs. The integrity of the person and family are maintained when the nurse appreciates the person and family holistically (the physical, emotional, and spiritual well-being domains).

Further, the integrity of the nurse, person and family are preserved by providing support to the person and family through the other dimensions of "*Connecting*", "*Doing For*", "*Empowering*", and "*Finding Meaning*". These dimensions of nursing care are necessary in order to develop a trusting relationship between the nurse, person, and their families.

Connecting. *Connecting* is comprised of three components within the relationship between the nurse, patient and family: making a connection, sustaining the connection and breaking the connection. Examples of strategies used to make the connection are establishing credentials and finding a common bond. In order to sustain the connection the nurse must be available to respond when needed. When breaking the connection the nurse will find an effective way to break the therapeutic relationship. This takes an enormous amount of time and the nurse must be confident in his/her decision so the feelings of all the parties involved are respected.

Doing For. The dimension of *Doing For* focuses on the physical care of the person. There are two components: taking charge and team playing. Taking charge refers to activities such as controlling pain and symptoms, making arrangements for care, and providing "direct hands on" care. Team playing requires the nurse to negotiate the

healthcare system on behalf of the person and their family. In this dimension the nurse uses resources that are extrinsic to the person and family.

Empowering. *Empowering* is a strength-giving dimension whereby the nurse directs the person and family in finding coping strategies. This dimension is multifaceted rather than task orientated or attitudinal. The components present in empowering are: facilitating (building on individual and family strengths), encouraging (acknowledging special abilities and/or negative feelings), mending (repairing family issues that arise related to the illness) and giving information (teaching and explaining).

Finding Meaning. *Finding Meaning* involves assisting the person and family to develop a perspective on the illness and its role in their lives. This dimension includes acknowledging the impending death, and helping the person and family to maximize available time.

Design of the Practicum Project

The design of the practicum consisted of two phases. Phase one involved identifying and distributing a survey to Manitoba nurses working in palliative care by sending a contact letter (Appendix A) to the CRNM requesting their assistance. Once the College granted approval, a letter of invitation (Appendix B), the survey (Appendix C) and a copy of the CHPCA Nursing Standards of Practice (Appendix D) were mailed by the CRNM to nurses (in accordance with the College's regulations). A copy of the CHPCA Nursing Standards of Practice was included for clarity and to ensure informed responses.

An important step in this practicum project was the development of the survey instrument. The questions were based on the CHPCA Nursing Standards of Practice. The

CHPCA Nursing Standards of Practice document clearly identified the role of the palliative care nurse and questions the nurse's beliefs, attitudes and perceptions of that role. The survey was 10 pages in length with approximately 145 questions and an estimated completion time of 30-45 minutes. Respondents had a 6 week time period (January 5, 2004 to February 15, 2004) to return the completed survey.

The second phase of the practicum design was to evaluate and analyze the survey feedback and develop a guideline for palliative care nurses to take back to their nursing educators to use when developing continuing palliative care nursing education programs. The feedback was analyzed by calculating frequencies according to the demographic information, each standard of practice and the numerical and narrative responses. All data were sorted first under the demographic information.

Data were analyzed using Davies and Oberle's (1990) supportive role framework. Nurses were asked a question regarding their overall preparedness to practice each standard. Responses were calculated in categories of Y=yes, N=no, S-sometimes and U-unsure. Nurses' responses to the items that make up each standard were separated under W-well prepared, S-somewhat prepared and N-not prepared. Nurses were asked to answer each standard under these groupings. A pre-study decision made by the investigator was that agreement to "somewhat prepared" and "not prepared" indicated continuing education was required. Responses were considered a priority for education programming if at least 51% of nurses responded that they were either "somewhat prepared" or "not prepared." Conversely, if responses to standards were rated equal to or greater than 50% "well-prepared" these items did not indicate further education. Also in this survey nurses were asked to comment on what education preparation was

needed to support their practice, as well as the preferred education delivery method for a continuing education program.

The palliative care nursing continuing education guideline was developed on the survey findings which were based on the CHPCA Nursing Standards of Practice. This guideline will be discussed further in Chapter Five. The responses to the standards were grouped and reflected in the guideline. In addition, method and approaches of education were also reflected in the guideline.

Ethical Considerations

Ethical approval of this practicum was obtained from the University of Manitoba Research Ethical Board in accordance with their policy statement. All information collected during the practicum was kept in strictest confidence. A promise of confidentiality was made to the participants in the covering letter. Also in the covering letter, it was made clear that the survey was not an evaluation of whether the nurse was performing in accordance with the standards but, rather, if they felt prepared to practice using the standards. There was no reference to name or identifying features during analysis or report writing, therefore the participants remained anonymous to the writer. Nurses in this survey were not required to give informed consent as their returned survey implied consent.

In order to ensure that the anonymity and confidentiality of participants were preserved, numerous precautions were undertaken. First, in recruiting potential participants, the CRNM was responsible for mailing the invitation letter and survey to potential participants. The writer did not have access to any names of potential participants. Potential participants were asked in the covering letter not to put their name

on the survey. The completed surveys were sent to CRNM at which time the survey was taken out of the envelope and placed in a folder marked with the writer's name on it for pick-up. The administrative assistant at CRNM made sure there was no identifying information on the returned surveys. If there was identifying information then that information was blackened out by the administrative assistant. The administrative assistant also destroyed all returned envelopes. The folder with the returned surveys was kept on the administrative assistant's desk. The writer checked on a regular basis for returned surveys (i.e., three times a week). Returned surveys were processed in this manner for a 6 week time period. Surveys returned past the 6 week time period were destroyed (shredded) by the administrative assistant. All data are stored in a locked cabinet in the writer's office at home and will be kept for 7 years at which time they will be destroyed. Data were grouped to prevent linking data to specific individual participants. In the covering letter there was a statement that participants were not required to fill out the survey as it is strictly done on a voluntary basis.

Chapter Four

Findings of the Practicum Project

Within this chapter, the findings of the practicum are organized following the survey format as follows; the demographic characteristics of the sample, nurse's responses to overall preparedness to practice each standard, responses to each item in all six standards, nurse's comments on challenges to continuing education preparation and recommended education methods.

Demographic Characteristics

A total of 107 surveys were mailed out to Manitoba palliative care nurses and 20 nurses responded to the survey. All respondents were female. Seventeen (85%) worked in Winnipeg and three (15%) outside Winnipeg. The majority of respondents worked in the community setting (45%), while the remainder worked in hospital (20%), on a palliative care unit (30%) or in a hospice (5%). A proportion of the respondents were diploma prepared nurses (50%), however 8 had a bachelor of nursing degree (40%) and 2 were master's prepared (10%). Nurses' ages ranged from 30-34 years (20%), 40-44 years (15%), 45-49 years (10%), 50-55 years (45%) and 55+ years (10%).

Years of nursing practice varied with the largest proportion of nurses having 21-30 years (35%), while 25% had between 1-10 years, 20% had 11-20 years and 20% had 31-40 years of practice. Even though the majority of nurses had 21-30 years of nursing practice, many of the nurses (65%) only had 1-5 years of palliative care nursing experience. Twenty-five percent of respondents had 6-10 years of palliative care nursing experience and only two nurses had more than 11 years experience.

The majority of nurses in the survey had received other additional palliative care related education. Self-education was the most frequently cited method of obtaining related palliative care education. Other related palliative care education included conferences (85%), courses (75%), participating in education (70%), and participation in related organizations (75%). The last category for related palliative care education was other, which listed items such as study groups, internet, self-mediation, telehealth, and journal club. In the other category, 30% of respondents had explored these modes of related palliative care education.

Overall Preparedness

Nurses were asked a question regarding their overall preparedness to practice each standard. Table 1 describes the respondent's overall preparedness to practice each standard.

Table 1

Overall Preparedness to Practice Each Standard

Standard	Yes	No	Sometimes	Unsure
Valuing- advocate for all persons and families with advanced illness?	70%	0	30%	0
Connecting- build a trusting relationship by taking time to get to know the person/family, establish credentials, explain the role of the team members, find a common bond, establishing a baseline assessment and communicating effectively the plan of care?	100%	0	0	0
Empowering- involve the person and family while uncovering and building on their own strengths by assessing, supporting the person/family's coping style and choices, assisting with decision making and assisting the person and family to deal with ethical dilemmas, while allowing them to vent and effuse frustration, assisting in healing relationships, and giving information on all aspects of care?	50%	5%	45%	0
Doing For- provide care based on best practice and/or evidence-based practice in the following areas: pain and symptom management, coordination of care and advocacy?	65%	0	35%	0
Finding Meaning- assist the person and family to find meaning in their life and their experience of illness.	55%	0	45%	0
Preserving Integrity- maintain self-worth and self-esteem in order to continue effective functioning by learning to give and receive, grieve, put aside personal agendas, replenish oneself and stay healthy, while supporting the person and family through all the above mentioned standards of practice?	65%	0	35%	0

Overall respondents felt prepared to practice using the CHPCA Nursing Standards of Practice. Of the nurses who felt prepared to use the CHPCA Nursing Standards, differences were found between education and practice settings as reported in Tables 2 and 3 for each standard.

Table 2

Reporting "Yes" to Preparedness on Standards

Education Level	Standard One-Valuing	Standard Two-Connecting	Standard Three-Empowering	Standard Four-Doing For	Standard Five-Finding Meaning	Standard Six-Preserving Integrity
Diploma	80%	100%	50%	60%	50%	60%
Degree	60%	100%	50%	70%	60%	70%

More degree nurses than diploma nurses reported feeling prepared to practice standards four (Doing For), five (Finding Meaning) and six (Preserving Integrity). Additionally, total years of experience as a palliative care nurse were examined and compared with education. The combined years of experience as a palliative care nurse for degree nurses were 52 years and for diploma nurses 74 years. Even though degree nurses had fewer years of experience as a palliative care nurse more felt prepared than diploma nurses to practice using the CHPCA Nursing Standards. Conversely more diploma nurses were more prepared regarding standard one (Valuing).

Table 3

Respondent Preparedness (% Responding "Yes") by Workplace Setting

Setting	Standard One-Valuing	Standard Two-Connecting	Standard Three-Empowering	Standard Four-Doing For	Standard Five-Finding Meaning	Standard Six-Preserving Integrity
Community Diploma-6 Degree- 3	66%	100%	44%	88%	33%	55%
Other Diploma-4 Degree- 7	72%	100%	54%	45%	72%	72%

Table 3 illustrates that, compared to nurses in the community, more nurses working in hospitals, palliative care units and hospices (other) felt prepared to practice standards one (Valuing), three (Empowering), five (Finding Meaning) and six (Preserving Integrity). Once again combined years of experience as a palliative care nurse were examined and compared to practice settings. The combined years of experience as a palliative care nurse for diploma nurses were 71 years and 55 years for degree nurses. Nurses in the other category had lower combined years of experience as palliative care nurses and felt more prepared to practice using the standards. Interestingly, nurses in the other palliative care settings group had more degree prepared nurses. Conversely, more community nurses than nurses in other settings were prepared for standard four (Doing For).

Responses to Standards/Practice Challenges

Survey questions were based on the CHPCA Nursing Standards of Practice document. Almost all nurses (85%) had received information on the CHPCA Nursing Standards of Practice prior to receiving the survey.

Results will be presented for the items that make up each standard and include whether nurses responded they were “well prepared”, “somewhat prepared” or “not prepared”. A pre-study decision made by the investigator was that agreement in “somewhat prepared” and “not prepared” indicated that continuing education was required. For instance, responses to standards were considered a priority for continuing education programming if at least 51% of nurses responded that they were either “somewhat prepared” or “not prepared”. Conversely, if nurses’ responses to standards

scored equal to or greater than 50% “well-prepared” these standards did not indicate further continuing education.

In addition, survey respondents were asked to comment on what educational preparation was needed to support their practice. These responses are not reported in the tables but rather comments to this question generated a theme termed, “practice challenges” that is found in the palliative care nursing continuing education guideline (Figure 2). In reporting the findings, the term “practice challenges” will be used to denote what education preparation nurses felt was needed to support their practice. Respondents were also asked what would be the best method to deliver continuing education and this area will be presented in the practicum findings and on the continuing education guideline as education delivery method.

The following section will describe a series of tables. Table 4 denotes overall priority palliative care nursing education needs for all six standards, consisting of nurse’s responses to standards and practice challenges. Tables 5 to 10 represent nurses’ responses to items that make up each standard.

Table 4

Priority Palliative Care Nursing Education Needs

Standard	Priority Palliative Care Nursing Education Needs
Standard One-Valuing	Nurses must know how to assist a dying patient to find meaning in their life in order to achieve the best quality of life as defined by the person who is dying.
Standard Two-Connecting	Nurses must be able to recognize the influence of cultural and spiritual values, beliefs, traditions and life patterns of a person and family on their illness experience in order to connect with them.
Standard Three-Empowering	Nurses need to feel comfortable exploring sensitive and emotional issues with persons and their families in order to build on person and family's strengths.
Standard Four-Doing For	Nurses must be knowledgeable and able to identify holistic care needs on a population based model of care in order to be active participants in the development of healthcare policy related to hospice palliative care nursing.
Standard Five-Finding Meaning	Palliative care nurses must understand the complexities of hope and suffering in order to enhance the human spirit and foster survival.
Standard Six-Preserving Integrity	Nurses need to participate in research activities appropriate to palliative care nursing practice in order to support the palliative care movement.

When examining the responses to standards and practice challenges from the six standards of practice, the above key statements summarize priority palliative care nursing education needs. These key statements can be used by educators as objectives when planning continuing education programming. All nurses in the survey felt prepared to practice standard two (Connecting). This is understandable because creating a therapeutic relationship is a nursing intervention required in all nursing curricula. As discussed in Tables 2 and 3, degree nurses felt more prepared with standards four (Doing For), five (Finding Meaning) and six (Preserving Integrity) regardless of the setting. This could be due to the fact that degree prepared nurses in Manitoba are taught palliative care in their undergraduate courses (Ross et al., 1996). Additionally degree nurses would also have

more exposure with research activities and therefore it is understandable they would feel more prepared with standard six.

In Tables 5 to 10 nurses' responses to the items that make up each standard are reported.

Table 5

Standard One – Valuing

Standard One-Valuing	Well Prepared	Somewhat Prepared	Not Prepared
Collaborate to create a social change toward dying	10 (50%)	08 (40%)	02 (10%)
Assist person to find meaning in life	07 (35%)	12 (60%)	01 (05%)
Achieve the best quality of life as defined by person	09 (45%)	11 (55%)	
Provide care sensitive to person's diversity	10 (50%)	10 (50%)	
Know how to access available resources	14 (70%)	06 (30%)	
Preserve integrity of self and others	17 (85%)	02 (10%)	
Involve person and family in plan of care	18 (90%)	02 (10%)	
Acknowledge person's unique characteristics	19 (95%)	01 (05%)	
Acknowledge death as a natural process of life	19 (95%)	01 (05%)	

Assisting persons to find meaning in life and achieving the best quality of life as defined by the person were two responses which nurses felt the least prepared to do. One explanation made by a nurse was "finding meaning in life is a private and individual experience and it can be complicated." Nurses found it difficult for the person to achieve the best quality of life because "of the variation in culture and religion" and because of the constant challenge "to meet all person's and family's needs from a holistic perspective." Responses to this standard are interconnected because nurses must know how to assist a dying person to find meaning in their life in order to achieve the best quality of life as defined by the person who is dying. However, nurses described valuing as a personal way of life and commented "valuing is part of your personal belief and all people should be treated this way" and "in order to believe in this standard one must also apply it to one's life."

Finally, nurses commented that practice challenges were focused on knowing how to access needed resources to support their palliative care practice, “accessing resources is a barrier, not sure what is out there.” This gap in knowledge pertained particularly to the ability to contact members of the interdisciplinary team as nurses did not know when to involve interdisciplinary team members.

Table 6

Standard Two - Connecting

Standard Two-Connecting	Well Prepared	Somewhat Prepared	Not Prepared
Assess influence of culture, spiritual and life patterns	09 (45%)	10 (50%)	1 (05%)
Demonstrate comfort when communicating death issues	16 (80%)	03 (15%)	1 (05%)
Initiate discussions relating to dying and death	17 (85%)	02 (10%)	1 (05%)
Help person establish priorities during dying process	10 (50%)	10 (50%)	
Review disease progression and goals of care	12 (60%)	08 (40%)	
Maintain professional boundaries	15 (75%)	05 (25%)	
Respect person's specific care requests	16 (80%)	04 (20%)	
Demonstrate sense of true presence	16 (80%)	04 (20%)	
Use verbal and non-verbal communication	17 (85%)	03 (15%)	
Seek to understand person's perceptions/expectations	17 (85%)	03 (15%)	
Listen actively as an integral part of communication	18 (90%)	02 (10%)	
Create an atmosphere to facilitate trust	19 (95%)	01 (05%)	
Explain role of nursing and other interdisciplinary team	19 (95%)	01 (05%)	
Respect confidentiality and privacy	19 (95%)	01 (05%)	
Respond in a sensitive and honest manner to questions	19 (95%)	01 (05%)	

Nurses felt unprepared in assessing the influence of cultural and spiritual values, beliefs, traditions, and life patterns of the person and family on their illness experience. This was also an area of concern in Standard One. Interestingly, despite feeling ill prepared to assess cultural and spiritual elements of care, nurses still felt overall prepared to connect with persons and families.

Two practice challenges were recognized by nurses in this standard; maintaining professional boundaries and lack of information regarding goals of care. When referring to professional boundaries one nurse stated, “barriers to professional boundaries must be maintained and can't be broken. A nurse may feel inadequate if crying in front of a

patient.” While another nurse felt “maintaining professional boundaries is a very challenging part of this job. To give the care and understanding that is required, one often feels deeply and therefore the challenge is keeping necessary boundaries.”

When it came to goals of care, one nurse wrote “missing information (i.e., x-ray results, or the information doctor gives to client) makes it difficult to organize the person’s goals of care,” while another nurse explained “I need more knowledge and information so that goals of care are appropriate and meaningful.” Nurses also felt that teamwork was important and all team members needed to respect each other’s opinions and share the common goals of the person and family. One nurse commented “being prepared in all the above items comes with experience and collaboration with others especially nurses.”

Nurses must know how to access necessary information to organize the person’s plan of care and also be able to communicate this information to the interdisciplinary team members and to the person and their families in order to create and maintain a trusting relationship. Nurses need to be knowledgeable about professional boundaries when developing a therapeutic relationship.

Table 7

Standard Three - Empowering

Standard Three-Empowering	Well Prepared	Somewhat Prepared	Not Prepared
Address sensitive and personal sexuality and intimacy issues	03 (15%)	13 (65%)	4 (20%)
Demonstrate awareness techniques of conflict resolution	06 (30%)	11 (55%)	3 (15%)
Collaborate with person to address ethical dilemmas	07 (35%)	10 (50%)	3 (15%)
Provide relevant information to developmental level	09 (45%)	08 (40%)	3 (15%)
Knowledgeable about emergencies (i.e., spinal cord)	10 (50%)	08 (40%)	2 (10%)
Address emotions with body image and self-esteem	09 (45%)	10 (50%)	1 (05%)
Knowledgeable about grief and bereavement	10 (50%)	09 (45%)	1 (05%)
Assist person with memory making and reminiscing	11 (55%)	08 (40%)	1 (05%)
Understand influence of family dynamics on illness	12 (60%)	07 (35%)	1 (05%)
Respect decisions to seek complementary therapies	12 (60%)	08 (40%)	
Identify priorities for care based on person's perspective	13 (65%)	07 (35%)	
Assist person to build on their own strengths	13 (65%)	07 (35%)	
Assist persons get information to make informed decisions	13 (65%)	07 (35%)	
Knowledgeable about signs of dying process	19 (95%)	01 (05%)	

Table 7 illustrates the difficulty nurses had with this standard. Concerns were noted about providing information according to the developmental level of the person and family. The developmental level (role, culture, personal experiences and cognitive development) of a person and their family when dealing with the crisis of death is unique and personal to each individual. All factors must be carefully evaluated in time of loss in order to aid the grieving person and family to use the crisis as a maturational rather than a destructive experience. One nurse felt, "she needed to learn more about the palliative phase because certain issues may cause family members to be distressed later."

Nurses also expressed difficulty with addressing sensitive, personal sexuality and intimacy issues, conflict resolution and addressing ethical dilemmas. Nurses commented on these issues under practice challenges.

Practice challenges that were identified by nurses were focused on time commitment and knowledge deficits in emotional and psychosocial distress. Nurses consistently drew attention to the intensive time commitment it takes to empower persons

and their families and commented “time consuming but important and often forgotten.” Nurses were also concerned that ethical dilemmas arise when attempting to empower persons and families and that this consumes a great amount of time. Timing was also a practice challenge to nurses if persons and family were not ready to communicate their feelings, “at times giving information is not a good idea, people often choose not to hear what is being said and this can be difficult.”

Nurses felt that they were more confident in “dealing with signs and symptoms of physical distress than with emotional or psychosocial distress.” Nurses also felt experience was an asset when empowering persons and their families, “many years of experience gives nurses insight into issues of dying and death” and “it is the best tool.” Nurses need to be comfortable exploring sensitive and emotional issues with persons and families in order to empower them and support them to build on their own strengths.

Table 8

Standard Four – Doing For

Standard Four-Doing For	Well Prepared	Somewhat Prepared	Not Prepared
Assist person in contacting relevant legal help	06 (30%)	08 (40%)	6 (30%)
Knowledge of special issues of children and elderly	06 (30%)	10 (50%)	4 (20%)
Use evidence-based model (WHO Ladder)	15 (75%)	01 (05%)	4 (20%)
Knowledge of drug availability and cost	08 (40%)	09 (45%)	3 (15%)
Advocate for policy related to end-of-life care	09 (45%)	09 (45%)	2 (10%)
Assume a leadership role with interdisciplinary team	12 (60%)	06 (30%)	2 (10%)
Facilitate transfer to different level of care setting	15 (75%)	03 (15%)	2 (10%)
Knowledge about equianalgesic conversions	10 (50%)	09 (45%)	1 (05%)
Use age appropriate assessment tools	10 (50%)	09 (45%)	1 (05%)
Demonstrate knowledge of opioid rotation	11 (55%)	08 (40%)	1 (05%)
Implement appropriate measures to treat side effects	12 (60%)	07 (35%)	1 (05%)
Facilitate transition into bereavement	13 (65%)	06 (30%)	1 (05%)
Educate public on end-of-life issues	13 (65%)	06 (30%)	1 (05%)
Participate in advanced care-planning (DNR)	14 (70%)	05 (25%)	1 (05%)
Knowledge of ATC, and breakthrough doses	17 (85%)	02 (10%)	1 (05%)
Assist person to maintain functional capacity, control	17 (85%)	02 (10%)	1 (05%)
Facilitate for pronouncement, notification of death	17 (85%)	02 (10%)	1 (05%)
Recognize the need for increased services	17 (85%)	02 (10%)	1 (05%)
Modified plan of care to address socioeconomic factors	10 (50%)	10 (50%)	
Understand different pain syndromes and types	12 (60%)	08 (40%)	
Recognize and anticipates common emergencies	12 (60%)	08 (40%)	
Collaborate with person and team develop care plan	13 (65%)	07 (35%)	
Provide information i.e., funeral preparation	13 (65%)	07 (35%)	
Use appropriate assessment tools for symptom	14 (70%)	06 (30%)	
Knowledge about opioids and adjuvant medications	14 (70%)	06 (30%)	
Advocate for appropriate pain management measures	14 (70%)	06 (30%)	
Conduct a comprehensive pain assessment	14 (70%)	06 (30%)	
Identify the multidimensional factors of total pain	15 (75%)	05 (25%)	
Accept person need to seek complementary therapies	15 (75%)	05 (25%)	
Assess person's support system to be at home	15 (75%)	05 (25%)	
Assess and respond to environmental safety risks	15 (75%)	05 (25%)	
Advocate the rights of person i.e., vulnerability	15 (75%)	05 (25%)	
Develop an effective plan to manage pain	16 (80%)	04 (20%)	
Conduct a comprehensive assessment of symptoms	16 (80%)	04 (20%)	
Knowledge of pain and symptoms in last hours of life	17 (85%)	03 (15%)	
Inform person how to access services 24 hours/day	17 (85%)	03 (15%)	
Identify barriers and myths to pain control (addiction)	17 (85%)	03 (15%)	
Monitor on a regular basis breakthrough pain medication	18 (90%)	02 (10%)	
Encourage person to keep team informed about pain	19 (95%)	01 (05%)	
Recognize the oral route is the preferred route	20(100%)		

Table 8 demonstrates that specific responses to this standard identified concerns that dealt with advocacy issues such as assisting the person and family in contacting relevant legal help (e.g., personal and advanced directives, power of attorney or proxy),

managing the critical need for attention to special populations such as children and the elderly, knowledge of drug availability and advocating for policy related to end-of-life care. It is understandable that palliative care nurses would not feel prepared in assisting persons and families in contacting relevant legal help and special groups because these are relatively new areas in palliative care. However, it is surprising that drug availability and advocating for policy related to end-of-life would be a concern. Recently Manitoba Health announced that all palliative care program patients' drug costs would be covered by the government. In terms of advocating for end-of-life policy nurses must be knowledgeable and able to identify holistic care needs on a population based model related to hospice palliative care nursing.

Practice challenges were expressed by one respondent as "I don't deal with children so I feel inadequate in pediatric palliative care." Also respondents felt that there was an "overwhelming amount of information especially with pain management" and "knowledge in the field is constantly changing and needs were being constantly updated."

Table 9

Standard Five – Finding Meaning

Standard Five-Finding Meaning	Well Prepared	Somewhat Prepared	Not Prepared
Demonstrate in-depth knowledge of hope	05 (25%)	13 (65%)	2 (10%)
Assist person to manage emotional response to illness	10 (50%)	08 (40%)	2 (10%)
Serving as a catalyst to finding meaning and hope	07 (35%)	12 (60%)	1 (05%)
Assist the person to feel balance with self and others	07 (35%)	13 (65%)	
Assist the person to clarify beliefs and values	07 (35%)	13 (65%)	
Support person to cope with uncertainty to illness	12 (60%)	08 (40%)	
Assist the person to maintain a sense of control	13 (65%)	07 (35%)	
Assist the person to access resources for spiritual needs	13 (65%)	07 (35%)	
Promote dignity and integrity	15 (75%)	05 (25%)	
Realize hope is constantly changing and is unique to person	17 (85%)	03 (15%)	

Responses to this standard show a higher percentage of nurses feeling "somewhat" and "not prepared" in four standard items: demonstrating in-depth

knowledge of the concept of hope, serving as a catalyst to finding meaning and hope for persons and families, assisting the person to feel a balance and connection with self and others, and assisting the person and family to clarify beliefs and values as appropriate. Many of the items are repetitive of priority responses identified in Standard One – Valuing. However the concept of hope is not. Palliative care nurses must understand the complexities of hope and suffering in order to enhance the human spirit and foster survival.

In the words of one nurse who identified significant practice challenges existed in the area of hope, “hope is a concept that I find difficult articulating for myself.” Another nurse felt “to find meaning and hope when facing a terminal illness is hard work for the person and family. The person’s past experiences will have an effect on his/her coping ability.” Nurses also felt that a “trusting relationship between the nurse and person was required and that nurses needed to be able to deal with their own issues,” and also if nurses had “many personal losses, and were able to make sense of their own loss, they would be able to assist others in a productive way but only if they had validated and learned from these times.” Nurses also felt it was important to “respect each person and family in order to recognize the different ways they cope and to always be aware of their emotions.” Once again nurses stressed the importance of the interdisciplinary team during these stressful times, “there are times when we need to refer to other available resources to assist the person and family.” When palliative care nurses help the person and their families develop a perspective on the illness and how this illness affects their lives, healthier outcomes are achieved for all parties involved.

Table 10

Standard Six – Preserving Integrity

Standard Six-Preserving Integrity	Well Prepared	Somewhat Prepared	Not Prepared
Participates in research activities appropriate to practice	07 (30%)	10 (50%)	3 (15%)
Strategies to resolve ethical concerns related to end of life	07 (30%)	11 (55%)	2 (10%)
Aware of the evolution of worldwide palliative care movement	09 (45%)	09 (45%)	2 (10%)
Integrates palliative care as a health promotion activity	10 (50%)	08 (40%)	2 (10%)
Recognizes measures to cope with multiple losses	12 (60%)	06 (30%)	2 (10%)
Recognizes values/beliefs may interfere with provision of care	16 (80%)	03 (15%)	1 (05%)
Integrates CHPCA Standards into practice	11 (55%)	09 (45%)	
Recognizes signs of stress that lead to self-exhaustion	11 (55%)	09 (45%)	
Adheres to national and provincial policy and procedures	12 (60%)	08 (40%)	
Identifies strategies for dealing with stress	14 (70%)	06 (30%)	
Knowledge of current principles and practices of palliative care	14 (70%)	06 (30%)	
Balances self-care needs complexities of dying and death	14 (70%)	06 (30%)	
Recognizes stress that lead to family caregiver exhaustion	14 (70%)	06 (30%)	
Values, beliefs, and reactions to life/death/spirituality/religion	15 (75%)	05 (25%)	
Demonstrates value of self by practicing self-care	16 (80%)	04 (20%)	
Provide comprehensive, compassionate, coordinated EOL care	16 (80%)	04 (20%)	
Acknowledges personal values/beliefs influence practice	18 (90%)	02 (10%)	
Participates in ongoing education related to palliative nursing	18 (90%)	02 (10%)	
Supports family caregiver in practicing self-care	18 (90%)	02 (10%)	

Nurses seemed “somewhat prepared” or “not prepared” to participate in research activities appropriate to practice, use strategies to resolve ethical concerns related to end-of-life care and be aware of the evolution of worldwide palliative care movement. To date, palliative care nursing research and education has been neglected in most nursing education programs and, therefore, given the fact that nurses are not prepared to participate in research activities appropriate to palliative care practice is understandable. Resolving ethical concerns was found to be a concern in Standard Three - Empowering and is addressed in that section.

It is surprising that these palliative care nurses would not be aware of the historical evolution of the modern hospice worldwide palliative care movement especially when Winnipeg had one of the first palliative care units in 1974. This

illustrates the need for continuing education programs to include this standard item in program planning.

An important practice challenge was voiced by nurses when integrating the standards into practice. Nurses felt “sometimes we know we are integrating standards into our practice but we don’t know how we do it.” However, another nurse recognized how the national standards could be integrated into practice and commented, “having reviewed the standards document made me aware of my strengths and weaknesses. Now I can work on my weaker areas of knowledge.” Yet another nurse expressed her future education goals as:

There is a constant change and growth in palliative care knowledge and ongoing education is essential. To have standards of practice is excellent and valuable and I shall continue to practice my palliative care nursing standards as well as learning on my own personal experience.

Many nurses viewed experience as a valuable resource that could influence their practice and contributed to expansion of their knowledge base. Experience was seen as a valuable resource as expressed by one nurse who commented:

So much of what we do on our own revolves around experience and one’s own views. I feel most of my education continues every day as a hands on the job experience and there is so much value in some of the experienced staff who have been in palliative care for many years. They make great mentors and resources and also valuable learning comes with personal experience either with family or have done a palliative care rotation.

Many nurses commented on self-care issues. One nurse commented:

I think it is important for the nurse to value herself and not feel she has to be perfect in all our nursing decisions. Sometimes we make errors and we need to be merciful to ourselves if we want to be merciful to others.

Another nurse recognized “the support from co-workers is very important to self-care” and “realizing my own self-worth and always working on self-esteem enables me to be an effective caregiver in this area.” Preserving Integrity is the core component of the Supportive Care Framework and important to the preservation of wholeness of both the person and nurse and is integral to the nurse’s functioning.

Education Delivery Method

In the survey nurses were also asked what would be the best education delivery method for each standard. The most commonly cited delivery methods for all standards included video, mentoring, role playing and workshops. The video education delivery method was mentioned in all 20 surveys. Samaroo (1996) found video learning as the top education delivery method in his study. Mentoring was the next education delivery method mentioned in the surveys. Although the literature did not report mentoring as a priority education delivery method, interdisciplinary team session and group discussions with interdisciplinary team members were encouraged. Patterson et al. (1997) found respondents in his study endorsed group discussions (67%) as the preferred method of education delivery. Interestingly several respondents from studies described in the literature review saw role playing as the least desired education delivery method (Jeffrey, 1994; Sellick et al., 1996), whereas respondents in this survey found role playing a favorable education delivery method. Workshops were also seen as a valuable resource by participants in this survey because they could practice effective communication skills

with each other. Other education delivery methods mentioned by nurse respondents included: small group discussions or lectures, on-line courses, team conferences, self-learning modules, case studies, books, articles and newsletters. One nurse provided details about education delivery methods and stated “provincial palliative care conferences are excellent at displaying the multi-dimensions of palliative care. You can’t just take courses on pain and symptom management you need to look at the multi-dimensional aspect and then put it all together.”

Other nurses felt that excellent education resources were: the Winnipeg Palliative Care website- www.palliative.info and the study modules for the palliative care certification exam. One nurse suggested that “it depends on the person’s ability to learn, education must be person centered and a variety of strategies are needed to reach all nurses.” Nurses viewed workshops as a venue for sharing skills and case studies provided insight into experienced nurses’ problem-solving techniques.

Summary

The majority of nurses in the survey felt prepared to practice using the CHPCA Nursing Standards. Differences were noted between degree nurses and diploma nurses. More degree nurses were prepared for standards four (Doing For), five (Finding Meaning) and six (Preserving Integrity) and diploma nurse were more prepared for standard one (Valuing). Both degree and diploma nurses were equally prepared for standard two (Connecting) and three (Empowering). Practice challenges were expressed as: limited time resources and knowledge deficits. Limited time resources were identified as a barrier to establishing a trusting and therapeutic relationship with persons and their families. Time constraints were also noted in the literature and also made reference to

time spent with persons and their families but also focused on time needed for continuing education sessions. Respondents in the survey mentioned several times that it was an asset if the nurse was experienced in death and dying issues such as dealing with ethical issues or conflict resolution because they did not take as much time to handle these issues.

Knowledge deficits were identified in areas such as: accessing palliative care resources, adapting to changing goals of care, assessing cultural and spiritual influences, addressing emotionally charged ethical dilemmas, maintaining professional boundaries, dealing with special palliative care populations, understanding the concepts of hope and finding meaning, understanding palliative care nursing research, and addressing self-care issues. From the responses to standards and practice challenges, six key statements were identified and summarized as priority palliative care nursing education needs and are reported on the palliative care nursing continuing education guideline (Table 4).

Overall nurses in this education needs survey provided insightful and helpful responses including educational approaches to learning that will be used to develop the palliative care nursing continuing education guideline presented in Chapter Five.

Chapter Five

Development of a Palliative Care Nursing Continuing Education Guideline

Discussion

The CHPCA Nursing Standards of Practice defines and sets boundaries that act as a guiding force for hospice palliative care nursing practice and education. Even though the number of research studies is limited, these standards are supported by evidence-based research findings that define the knowledge base and competencies of palliative care nursing practice (Davies & Oberle, 1990). The Canadian Nurses Association's (1998) Policy Statement encourages nurses to use professional standards in their area of practice in order to practice safely and competently. In Manitoba, no formal continuing education plans have been developed to prepare nurses to incorporate the CHPCA Nursing Standards of Practice into their clinical practice.

Feedback from the needs assessment survey given to Manitoba palliative care nurses provided information that revealed continuing educational needs. This discussion is organized according to four summary statements derived from a review of the literature. The practicum findings have contributed to the developmental process of a palliative care nursing continuing education guideline as presented in Figure 2.

1. Gaps exist between palliative care nursing education and nursing practice.

Growth in palliative care knowledge is creating a complex theory base that is producing significant gaps between palliative care nursing education and palliative care nursing practice (Dowell, 2002; Jodrell, 2001; Rosser, 1997). Gaps between palliative care nursing education and nursing practice were apparent in responses for all six standards. For instance, in Standard One, 70% of nurses felt prepared to advocate for all

persons at end-of-life, but did not feel prepared to assist persons to find meaning in life and achieve the best quality of life as defined by the person. A gap is created between practice and knowledge because nurses identified practice challenges to be able to meet all persons and family's private and individual needs, their readiness for information and not knowing how to access appropriate resources. In order to address the education/practice gap that exists in Standard One, this project suggests that priority education programming might focus on how to access palliative care resources and interdisciplinary involvement that practices a teamwork philosophy.

In Standard Two, all nurses (100%) felt prepared to connect with persons and their families in order to establish a therapeutic relationship. Yet these nurses felt unprepared in conducting a cultural or spiritual assessment. Nurses also struggled with being able to maintain professional boundaries in the nurse/patient/family relationship and, as well, had difficulty developing appropriate and meaningful goals of care. Once again the challenge of working in an interdisciplinary model of care was raised. Education programming must be geared to address the valuable information gathering process and planning of care development that can be accomplished in interdisciplinary rounds and family conferences. In addition, the importance of nursing professionals requiring the skills of conducting a cultural and spiritual assessment is essential to quality patient care.

Standard Three responses were split 50%-50% relating to nurses ability to empower the person and their families. Key practice challenges identified in this standard were lack of time commitment, knowledge deficits in addressing sensitive and emotionally charged issues and inability to handle ethical dilemmas. Raudonis et al.

(2002) found in their study of 164 nurses in 24 long term care facilities that nurses struggled with the philosophy and principles of palliative care and expressed difficulty when addressing ethical dilemmas and other sensitive and emotionally charged issues. Based on the results of this survey, nurses might benefit from education programs that included information on time management skills, ethical decision-making framework, conflict resolution skills, effective communication skills, and human development relating to terminally ill persons and their families.

Several gaps were apparent in Standard Four. Knowledge of drug availability and advocating policy related to end-of-life care were evident in this survey. With the recent announcement of the Manitoba Health Palliative Care Drug Program and other new governmental palliative care initiatives, it is surprising nurses felt a knowledge deficit in this area. However, it was not surprising a knowledge deficit existed with care of special populations. This is a relatively new field in palliative care especially with the pediatric population.

Priority education should be geared to keep palliative care nurses well informed of government initiatives such as the Manitoba Health Palliative Care Drug Access Program and Winnipeg Regional Health Authority Advanced Care Planning Initiative, as well as new evidenced-based research on interdisciplinary and collaborative practice and issues specific to the elderly and pediatric populations.

For Standard Five, the biggest education/practice gap existed between the concepts of hope and finding a balance between hope and suffering. Education priorities can examine the dimensions of hope and the relationship between hope and coping as well as the relationship between the meaning of hope and the amelioration of suffering.

Finally, responses to Standard Six found education/practice gaps existed between having knowledge about the CHPCA Nursing Standards of Practice and the goal of palliative nursing research, but were unsure of how to implement this knowledge into their practice. Priority education must include education programming based on the CHPCA Nursing Standards of Practice and identify goals and barriers of palliative care nursing research.

The palliative care nursing continuing education guideline (Figure 2) summarizes the reflected practice challenges and priority education needs.

2. The nurse's role at the bedside of a dying patient can have a profound effect on the quality of life of the dying and the bereaved.

The CHPCA Standards of Nursing Practice clearly identifies the role of the palliative care nurse at the bedside and the literature supports the importance of palliative care nurses to implement the CHPCA Nursing Standards into their practice. The lack of time was frequently mentioned as the key barrier to the provision of high quality care. Time was expressed as lack of time to establish a therapeutic relationship, how valuable time was when an experienced nurse dealt with ethical and emotionally charged issues, and the lack of time nurses could actually spend with persons and their families. Lastly, time constraints were also expressed as barriers to attending continuing education sessions. Well-prepared nurses need adequate educational resources and support (Dowell, 2002) in order to be effective at the bedside. Time commitment is an area that palliative care nurses will need to bring to the attention of healthcare administrators and policy makers. Education programming needs to be geared at time management techniques so nurses do have the available time to establish therapeutic relationships, handle ethical

dilemmas, conflict issues and attend continuing education sessions. This need is reflected on the palliative care nursing continuing education guideline.

3. Nursing Standards of Practice set boundaries and act as a guiding force for hospice palliative care nursing practice and education.

A copy of the CHPCA Nursing Standards of Practice was sent to all nurses who designated palliative care as their area of specialty on the CRNM 2004 registration form. It is the goal of the CHPCA Nursing Standards Committee that all palliative care nurses incorporate these standards into their practice. It is only then that a standard of palliative care nursing will be defined and care may be delivered in a consistent manner to all Manitobans who are living with and dying from advanced illness. Nurses in the practicum survey agreed and felt the standards were "excellent, very valuable, and comprehensive." By reviewing the standards document, nurses were able to identify their own individual education needs. Several nurses commented that reading the standards initiated awareness of personal strengths and weaknesses in practice and initiated a response to improvement. Therefore this survey, based on the CHPCA Nursing Standards of Practice, has provided nurses with learning opportunities and contributed to the development of a palliative care nursing continuing education guideline. In this way program planning will be based on the CHPCA Nursing Standards of Practice.

4. Responding to nurses' learning needs in ways that are relevant to them is the most effective way of facilitating change in their behavior.

Kristjanson and Balneaves (1995) surveyed 100 experienced nurses from across Canada to obtain information about Canadian palliative care nurses' perceptions of practice and professional issues. Two key issues of importance were identified: standards

of practice for palliative care nursing needed to be developed and educational needs of palliative care nurses needed to be assessed. Standards of Practice have now been developed. This is evidence that, by asking palliative care nurses what they want in ways that are relevant to them, is the most effective way of facilitating change in practice. Asking Manitoba palliative care nurses if they are prepared to use the CHPCA Nursing Standards appears to be relevant and will facilitate a change in their practice.

Nurses in the survey were also asked what education delivery method should be used to educate palliative care nurses. Survey respondents in this practicum project listed the most frequently requested as video, mentoring and role playing. However, small group discussions, on-line courses, team conferences, self-learning modules, workshops and case studies were also frequently mentioned. Nurses viewed workshops as a venue for sharing skills and that case studies provided insight into experienced nurses' problem-solving abilities and techniques.

Presentation of the Palliative Care Nursing Continuing Education Guideline

This practicum project has contributed to the implementation phase of the CHPCA Nursing Standards of Practice by developing a palliative care nursing continuing education guideline. Once again the CRNM will provide their assistance by distributing a copy of this guideline to all Manitoba palliative care nurses. It is hopeful that the following guideline will be used by palliative care nursing educators in program planning.

Figure 2. Palliative care nursing continuing education guideline.

Palliative Care Nursing Continuing Education Guideline	
<p>In Canada, palliative care nurses are concerned about standards of practice and educational preparation to meet their needs (Kristjanson & Balneaves, 1995). A needs assessment survey of Manitoba palliative care nurses was conducted to ascertain their perceived continuing educational needs. A total of 107 surveys were mailed out and 20 nurses responded to the survey. This guideline is based on the results provided by 20 palliative care nurses who completed and returned the survey. The Canadian Hospice Palliative Care Association Nursing Standards of Practice formed the structure of this survey. Review of the literature contributed to the identification of four summary statements that articulate the need for palliative care nurses to incorporate the CHPCA Nursing Standards into their practice. The survey findings provided valuable information essential to future palliative care educational programming.</p>	
Demographics	
<p>The majority of nurses in this survey (45%) were between the ages of 50-55 years of age and all were female. Even though 35% had between 21-30 years of nursing experience 65% had between 1-5 years experience as a palliative care nurse. Also many of these nurses had attended other palliative care education opportunities that were self-initiated; self-education (90%), conferences (85%), courses (75%) and were members of palliative care organizations (75%). These statistics are an indication that these nurses are extremely motivated to attend continuing education opportunities. In addition 85% of nurses had received information on the Canadian Hospice Palliative Care Nursing Standards of Practice prior to completing this survey.</p>	
Priority Palliative Care Nursing Education Needs	
<p>Valuing – Nurses must know how to assist a dying patient to find meaning in their life in order to achieve the best quality of life as defined by the person who is dying.</p>	
<p><u>Practice Challenges</u></p> <ul style="list-style-type: none"> • meeting all persons and family's private and individual needs • acknowledging person and family's readiness for information • identifying appropriate resources and knowing how to access them 	<p><u>Priority Education Need</u></p> <ul style="list-style-type: none"> ▪ Palliative care resources availability and access that emphasizes the physical, emotional, psychosocial and spiritual needs of the person and family ▪ Interdisciplinary practice and team collaboration
<p>Connecting – Nurses must be able to recognize the influence of cultural and spiritual values, beliefs, traditions and life patterns of a person and family on their illness experience in order to connect with them.</p>	
<p><u>Practice Challenges</u></p> <ul style="list-style-type: none"> • changing goals of care not established • assessing influence of cultural and spiritual values • maintaining professional boundaries with persons and their families 	<p><u>Priority Education Need</u></p> <ul style="list-style-type: none"> ▪ Guidelines for interdisciplinary rounds and family conference to assist with decision-making and establishing goals of care ▪ Counseling skills (maintaining boundaries) ▪ Conducting a cultural and spiritual assessment

<i>Empowering</i> – Nurses need to feel comfortable exploring sensitive and emotional issues with persons and their families in order to build on persons and family’s strengths.	
<u>Practice Challenges</u>	<u>Priority Education Need</u>
<ul style="list-style-type: none"> • time commitment • knowledge deficit in addressing sensitive and emotionally charged issues that can lead to conflict • inability to handle ethical dilemmas 	<ul style="list-style-type: none"> ▪ Time management skills ▪ Ethical decision-making framework/conflict resolution skills ▪ Human development related to terminally ill persons and their families ▪ Effective communication skills ▪ Philosophy and principles of palliative care
<i>Doing For</i> – Nurses must be knowledgeable and able to identify holistic care needs on a population based model of care in order to be active participants in the development of healthcare policy related to hospice palliative care nursing.	
<u>Practice Challenges</u>	<u>Priority Education Need</u>
<ul style="list-style-type: none"> • unaware of drug availability resources • knowledge deficit in dealing with special populations • unaware of legal resources 	<ul style="list-style-type: none"> ▪ Manitoba Health Palliative Care Drug Access Program ▪ Winnipeg Regional Health Authority Advance Care Planning Initiative ▪ Issues specific to the elderly and pediatric palliative care population
<i>Finding Meaning</i> – Palliative care nurses must understand the complexities of hope and suffering in order to enhance the human spirit and foster survival.	
<u>Practice Challenges</u>	<u>Priority Education Need</u>
<ul style="list-style-type: none"> • unaware of the concept of hope • unaware of acting as a catalyst to finding meaning and hope • unaware of assisting others to find a balance between hope and suffering 	<ul style="list-style-type: none"> ▪ Dimensions of hope and relationship between hope and coping ▪ The meaning of hope and dying ▪ The amelioration of suffering
<i>Preserving Integrity</i> – Nurses need to participate in research activities appropriate to palliative care nursing practice in order to support the palliative care movement.	
<u>Practice Challenges</u>	<u>Priority Education Needs</u>
<ul style="list-style-type: none"> • integrating standards into practice yet not knowing how to articulate them • knowing the goals of palliative care nursing research • identify of self-care techniques • being aware of the palliative care movement 	<ul style="list-style-type: none"> ▪ Education programming based on the CHPCA Nursing Standards of Practice ▪ Goals and barriers of palliative care nursing research ▪ Compassion fatigue and critical incident stress ▪ Palliative Care Movement (Senate Committee on Strategy for EOL Care)

<p>The Nurse's role at the bedside of a dying patient can have profound effect on the quality of life of the dying and bereaved.</p>
<p><i>Nurses provide more care to dying persons and their families than any other healthcare professional (Ferrell, Virani, & Grant, 1999; Pimple, Schmidt, & Tidwell, 2003) and nurses are in the unique position to make a substantial difference to persons and their families at end-of-life (Sherman, Matzo, Rogers, McLaughlin, & Virani, 2002). The review of the literature and practicum findings supported time constraints as an important practice challenge. Time was expressed as; lack of time to establish a therapeutic relationship, experienced nurses took less time to deal with ethical and emotionally charged issues, lack of protected learning time and the amount of time actually spend at the bedside. The time spent at the bedside is one area that practicing palliative care nurses must advocate for. Nurses must lobby healthcare administrators and policy makers that more time must be devoted at the bedside (in all healthcare settings) when caring for terminally ill persons and their families.</i></p>
<p>Nursing Standards of Practice set boundaries and act as a guiding force for hospice palliative care nursing practice and education.</p>
<p><i>The Canadian Nurses Association's (CNA) Policy Statement (1998) encourages nurses to use professional standards in their specialty area of practice in order to practice safely and competently. The CNA now recognizes Hospice Palliative Care Nursing as the twelfth specialty area in nursing. Nurses found the standards to be valuable and comprehensive. Also nurses commented that reading the standards made them aware of their areas of strengths and weaknesses and now they could work on weaker areas of knowledge. To access a copy of the Hospice Palliative Care Nursing Standards of Practice for educational program development please visit www.chpca.net or www.palliative.info</i></p>
<p>Responding to nurse's learning needs in ways that are relevant to them is the most effective way of facilitating change in their behavior.</p>
<p><i>White, Coyne, and Patel (2001) strongly suggest that identifying nurse's educational needs is the first step toward changing practice. Survey respondents listed the most common education delivery method for all standards by viewing a video and then mentoring and role playing. However, small group discussions, on-line courses, team conferences, self-learning modules, workshops and case studies were also frequently mentioned. Nurses viewed workshops as a venue for sharing skills and that case studies provided in sight into experienced nurse's problem-solving abilities and techniques.</i></p>
<p>Evaluation</p>
<p><i>Ferrell (1998) pointed out that in order to ensure that palliative care nursing education is effective evaluation initiatives need to be undertaken. In past research focused on how education and training should be provided but failed to show what education and training needs would improve the quality of patient care. Future research direction must focus on valid and reliable evaluation tools to determine if the palliative care nursing continuing education guideline was a valuable tool for nursing educators.</i></p>

Limitations of the Practicum Project

It must be acknowledged that there were limitations in this practicum project. The first limitation was that respondents were all females and therefore male palliative care nurses were not represented. Second, only three respondents were from rural Manitoba and so findings cannot be generalized to a rural population. Third, only 20 nurses

responded to the survey and therefore the results cannot be generalized to the population as a whole. Generalization is further hampered by the fact that a number of nurses who responded to the survey were over the age of 40 years (80%) and therefore younger aged palliative care nurses were not represented. Conversely the majority of the nurses who responded to the survey only had 1-5 years experience (65%) in palliative care nursing and therefore nurses with more experience were not sufficiently represented.

In addition, 107 surveys were sent to Manitoba palliative care nurses with a response rate of 18%. The survey was lengthy and consisted of approximately 145 questions with an estimated completion time of 30-45 minutes. Due to the length of the survey it could be concluded that only committed palliative care nurses completed this survey because they took the time to fill it out. However, it cannot be concluded that the findings in this practicum project reflect the opinions of the entire palliative nurse population in Manitoba. Rather, it is assumed that the findings of this practicum project represents a starting point for future researchers to explore the preparedness of Manitoba palliative care nurses to use the CHPCA Nursing Standards of Practice.

Future Directions

Manitoba palliative care nurses have valuable information to share with their continuing educators about their preparedness to use the CHPCA Nursing Standards of Practice. By asking these nurses how prepared they are to incorporate the CHPCA nursing standards into their practice and using their feedback to develop a palliative care nursing continuing education guideline for them to take back to their nursing educators will help to guide future research about the needs of hospice palliative care nurse's needs.

Future research directions must focus on valid and reliable evaluation tools to determine if this palliative care nursing continuing education guideline was a valuable source for continuing nursing educators. In addition a follow-up survey conducted in the same manner as this practicum project needs to be done preferable in a two year time period to assess if new or unresolved practice challenges exist. Any future research project must strengthen the work of palliative care nurses by implementing survey techniques that will encourage a better response rate. The practicum project may have provided more substantial findings had a focus group been established to discuss continuing educational needs areas that nurses identified. Also future research may explore the differences between degree and diploma nurses preparedness to use the CHPCA Nursing Standards of Practice. This would have an impact on the degree of education intervention needed. As well, comparing different settings and age groups would need to be included in future research. It is only through ongoing research and evaluation that Manitoba palliative care nurses continuing education needs will be addressed.

Conclusion

The interrelationship between continuing education, clinical competence and high quality and compassionate palliative care practice is complex and needs to be handled in an education format that is conducive to front-line palliative care nurses' needs. Manitoba palliative care nurses possess the compassion to care for terminally ill persons and their families and want to be well-prepared and competent to deliver care. This practicum project is a beginning step in identifying continuing education needs of Manitoba

palliative care nurses and addressing these needs through continuing education programming based on the CHPCA Nursing Standards of Practice.

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Appendix A

College of Registered Nurses of Manitoba
211 Broadway Avenue
Winnipeg, Manitoba

Attention: Ms. Diane Wilson-Mate, Director of Policy & Registry

Dear Ms. Wilson-Mate:

Re: Graduate Practicum Project- University of Manitoba

My name is Darlene Grantham. I am a student in the Master of Nursing Program at the University of Manitoba. As part of my program, I am conducting a needs assessment survey entitled *Preparedness of Manitoba Palliative Care Nurses to Practice Using the Canadian Hospice Palliative Care Nursing Standards*. Nurses who care for terminally ill persons and their families will be expected to guide them through the process of dying and often be present at the event of death. As the demand for specialty palliative care services increases so will the educational needs of front-line palliative care nurses. How prepared these nurses are reflects the person's and family's end-of-life care. The Canadian Hospice Palliative Care Nursing Standards Committee has developed standards of practice for palliative care nurses. These standards have been circulated across Canada to various nursing stakeholders. To date nursing educators have not been given clear direction on how to implement the Canadian Hospice Palliative Care Nursing Standards of Practice.

The purpose of this practicum is to conduct a needs assessment of palliative care nurses in the Province of Manitoba by distributing a survey that is based on the Canadian Hospice Palliative Care Nursing Standards of Practice. Feedback from palliative care nurses will be used to develop a palliative care educational program guideline for continuing educators to use when doing program development for palliative care nursing practice. Hopefully future palliative care educational program planning will be based on this guideline. Participants will be asked not to put their names on the survey. The goal of this survey is not to evaluate whether nurses are practicing under the standards but rather, if they feel prepared to practice using the national palliative care standards. This practicum project has been approved by the Nursing Research Ethics Board and if you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122 or e-mail Margaret_Bowman@umanitoba.ca.

To assist me with distribution of this survey I request approval from your organization. I will provide you with a covering letter of explanation, the mail-out surveys, an empty envelope addressed to the College (so participants can mail the completed survey back to the College) and a copy of the standards packaged in a blank envelope that will have postage applied for you to mail out to all nurses who identify themselves as palliative care nurse on the 2004 registration form. As the completed surveys are returned the student will pick them up on a regular basis (three times a week) for a six week period. After the six week period please destroy any late surveys. As surveys are returned kindly have the administrative assistant check the surveys to ensure the participant's name is not on the survey. Also please have the administrative assistant destroy the envelope. I will provide you with a file folder with my name on it so surveys can be placed in this folder until I pick them up. Once the data has been collected and the guideline is prepared I will once again ask that you mail-out the guidelines to all the palliative care nurses. Once again I will provide the envelopes and postage. Participation in this project is entirely voluntary. All data provided will remain strictly confidential. The only people with access to it will be the members of my practicum committee (Dr. Lynn Scruby, Dr. Roberta Woodgate, and Dr. John Bond) and myself. All committee members are Professors of the University of Manitoba. On completion of this project, findings will be submitted to a variety of journals for publication or findings may be presented at conferences. All data will be stored in a locked cabinet in the student's office at home and destroyed after seven years. If you have any questions regarding this practicum project please contact my practicum committee Chair, Dr. Lynn Scruby, by phoning (204) 474-6659. Thank-you for your assistance.

Yours truly,
Darlene Grantham

Appendix B

Dear Colleague:

Re: Graduate Practicum Project- University of Manitoba

My name is Darlene Grantham. I am a student in the Master of Nursing Program at the University of Manitoba. As part of my program, I am conducting a needs assessment survey entitled *Preparedness of Manitoba Palliative Care Nurses to Practice Using the Canadian Hospice Palliative Care Nursing Standards*. Nurses who care for terminally ill persons and their families will be expected to guide them through the process of dying and often be present at the event of death. As the demand for specialty palliative care services increases so will the educational needs of front-line palliative care nurses. How prepared these nurses are reflects the person's and family's end-of-life care. The Canadian Hospice Palliative Care Nursing Standards Committee has developed standards of practice for palliative care nurses. I have included a copy of the Canadian Hospice Palliative Care Nursing Standards of Practice for your review prior to completing the survey. To date nursing educators have not been given clear direction on how to implement the Canadian Hospice Palliative Care Nursing Standards of Practice.

The purpose of this practicum is to conduct a continuing education needs assessment of palliative care nurses in the Province of Manitoba by distributing a survey that is based on the Canadian Hospice Palliative Care Nursing Standards of Practice (a copy of the standards is enclosed for your reference). Feedback from palliative care nurses will be used to develop a palliative care educational program guideline for continuing educators to use when doing program development for palliative care nursing practice. Hopefully future palliative care educational program planning will be based on this guideline. The goal of this survey is not to evaluate whether palliative care nurses are practicing under the standards but rather, if they feel prepared to practice using the national palliative care standards. In addition the information will not be used to evaluate your work performance and your employer will not have access to what you say. This practicum project has been approved by the Nursing Research Ethics Board and if you have any concerns or complaints about this project you may contact the Human Ethics Secretariat at 474-7122 or e-mail Margaret_Bowman@umanitoba.ca.

To assist me with this project I ask that you complete the enclosed survey. The survey should not take anymore than 30-45 minutes to complete. Participation in this project is entirely voluntary. All data provided will remain strictly confidential. All data information will be kept in a locked cabinet in my office at home and stored for seven years then destroyed. Please do not include your name on the survey. Once you have completed the survey place it in the self-addressed envelope. The envelope has sufficient postage on it. You may keep the copy of the Canadian Hospice Palliative Care Nursing Standards of Practice. The only people with access to it will be the members of my practicum committee (Dr. Lynn Scruby, Dr. Roberta Woodgate, and Dr. John Bond) and myself. My committee members are all Professors of the University of Manitoba. On completion of this project, findings will be submitted to a variety of journals for publication or be presented at conferences. A copy of the continuing education guideline, based on the findings, will be mailed to all nurses included in the survey. It is recommended that palliative care nurses forward the guideline to continuing education nurses. Kindly return the completed survey back within 4-6 weeks after you have received it. If you have any questions regarding this practicum project please contact my practicum committee Chair, Dr. Lynn Scruby, by phoning (204) 474-6659. Thank-you for your assistance.

Yours truly,

Darlene Grantham

Appendix C

Continuing Education Needs Assessment Survey

A. Background Information:**Gender:**

Female _____

Male _____

Place of Employment:

Winnipeg _____

Outside Winnipeg _____

Type of Facility: (Please include name)

Hospital _____

Long Term Care Facility _____

Personal Care Home _____

Outpatient Clinic _____

Community Health Center _____

Private Nursing Agency _____

Palliative Care Unit _____

Hospice _____

Community (Home) _____

Other _____

Education Information

___ Diploma

___ Baccalaureate

___ Masters

___ Doctorate

___ CNA Certification

___ Other _____

Age Range

20-24 _____ 25-29 _____ 30-34 _____

35-39 _____ 40-44 _____ 45-49 _____

50-55 _____ 55+ _____

How many years have you worked as a registered nurse? _____

How many years have you worked as a palliative care nurse? _____

Other palliative care related experience:

Conferences _____

Courses _____

Participation in education _____

Participation in related organizations _____

Self-education through journals, books _____

Other _____

Thank you. The background information will be helpful. Now I would like to ask you some questions about how well prepared you feel to be able to conduct your practice using the Canadian Hospice Palliative Care Nursing Standards of Practice.

To begin with, have you ever received any information about the Canadian Hospice Palliative Care Nursing Standards of Practice?

_____ Yes _____ No

B. Canadian Hospice Palliative Care Nursing Standards of Practice

Standard I: Valuing-the hospice palliative care nurse believes in the intrinsic worth of others, the value of life and that death is a natural process.

As a palliative care nurse do you feel prepared to advocate for all persons and families with advance illness? Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- | | | | |
|---|-------|-------|-------|
| - know how to access available resources | ___ W | ___ S | ___ N |
| - provide care sensitive to person's diversity | ___ W | ___ S | ___ N |
| - involve person and family in plan of care | ___ W | ___ S | ___ N |
| - acknowledge person's unique characteristics | ___ W | ___ S | ___ N |
| - assist person to find meaning in life | ___ W | ___ S | ___ N |
| - achieve the best quality of life as defined by person | ___ W | ___ S | ___ N |
| - acknowledge death as a natural process of life | ___ W | ___ S | ___ N |
| - preserve integrity of self and others | ___ W | ___ S | ___ N |
| - collaborate to create a social change towards dying | ___ W | ___ S | ___ N |

Please comment:

a. What education preparation is needed to support palliative care nurses for this standard?

b. What is the best education method to deliver continuing education for this standard?

Standard II: Connecting-the hospice palliative care nurse establishes a therapeutic connection (relationship) with the person and their family through making, sustaining and closing the relationship.

As a palliative care nurse how well prepared do you feel to build a trusting relationship by taking time to get to know the person/family, establish credentials, explain the role of the team members, find a common bond, establishing a baseline assessment and communicating effectively the plan of care?

Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- | | | | | | | |
|--|-----|---|-----|---|-----|---|
| - create an atmosphere to facilitate trust | ___ | W | ___ | S | ___ | N |
| - seek to understand person's perceptions/expectations | ___ | W | ___ | S | ___ | N |
| - listen actively as an integral part of communication | ___ | W | ___ | S | ___ | N |
| - explain role of nursing and other interdisciplinary team | ___ | W | ___ | S | ___ | N |
| - assess influence of culture, spiritual and life patterns | ___ | W | ___ | S | ___ | N |
| - use verbal and non-verbal communication | ___ | W | ___ | S | ___ | N |
| - demonstrate sense of true presence | ___ | W | ___ | S | ___ | N |
| - respect confidentiality and privacy | ___ | W | ___ | S | ___ | N |
| - respect person's specific care requests | ___ | W | ___ | S | ___ | N |
| - maintain professional boundaries | ___ | W | ___ | S | ___ | N |
| - demonstrate comfort when communicating death issues | ___ | W | ___ | S | ___ | N |
| - initiate discussions relating to dying and death | ___ | W | ___ | S | ___ | N |
| - respond in a sensitive and honest manner to questions | ___ | W | ___ | S | ___ | N |

- help person establish priorities during dying process ___W ___S ___N
- review disease progression and goals of care ___W ___S ___N

Please comment:

b. What education preparation is needed to support palliative care nurses for this standard?

c. What is the best education method to deliver continuing education for this standard?

Standard III: Empowering-the hospice palliative care nurse provides care in a manner that is empowering for the person and family.

As a palliative care nurse how well prepared do you feel to involve the person and family while uncovering and building on their own strengths by assessing and supporting the person and family's coping style, assisting with decision making and supporting choices made by the person and family. Assisting the person and family to deal with ethical dilemmas, allowing the family to vent and effuse frustration, assisting in healing relationships, and giving information on all aspects of care?

Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- identify priorities for care based on person's perspective ___W ___S ___N
- assist person to build on their own strengths ___W ___S ___N
- address sensitive and personal issues of sexuality and intimacy ___W ___S ___N
- address emotions associated with body image and self-esteem ___W ___S ___N
- respect decisions to seek complementary therapies ___W ___S ___N
- assist persons to gather information to make informed decision ___W ___S ___N
- demonstrate awareness of techniques of conflict resolution ___W ___S ___N
- collaborate with person to address ethical dilemmas ___W ___S ___N
- understand influence of family dynamics on illness ___W ___S ___N

- assist person with memory making and reminiscing ___W ___S ___N
- provide relevant information to developmental level ___W ___S ___N
- knowledgeable about emergencies (i.e., spinal cord) ___W ___S ___N
- knowledgeable about grief and bereavement ___W ___S ___N
- knowledgeable about signs of dying process ___W ___S ___N

Please comment:

b. What education preparation is needed to support palliative care nurses for this standard?

c. What is the best education method to deliver continuing education for this standard?

Standard 1V: Doing For-the hospice and palliative care nurse provides care based on best practice and/or evidence-based practice in the following areas: pain and symptom management, coordination of care and advocacy.

As a palliative care nurse how well prepared do you feel to conduct a comprehensive assessment of pain and other symptoms using valid appropriate tools and to incorporate accepted principles of pain and symptom management into delivery of care. Coordination of care involves collaborating with and taking a leadership role in the interdisciplinary team?

Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- identify the multidimensional factors of total pain ___W ___S ___N
- advocate for appropriate pain management measures ___W ___S ___N
- develop an effective plan to manage pain ___W ___S ___N
- accept persons need to seek complementary therapies ___W ___S ___N
- knowledge of special issues of children and elderly ___W ___S ___N
- understand different pain syndromes and types ___W ___S ___N

- use evidence-based model (WHO ladder)	___	W	___	S	___	N
- identify barriers and myths to pain control (addiction)	___	W	___	S	___	N
- conduct a comprehensive pain assessment	___	W	___	S	___	N
- use age appropriate assessment tools	___	W	___	S	___	N
- implement appropriate measures to treat side effects	___	W	___	S	___	N
- demonstrate knowledge of opioid rotation	___	W	___	S	___	N
- encourage person to keep team informed about pain	___	W	___	S	___	N
- monitor on a regular basis breakthrough pain medication	___	W	___	S	___	N
- knowledge about equianalgesic conversions	___	W	___	S	___	N
- knowledge about opioids and adjuvant medications	___	W	___	S	___	N
- recognize that the oral route is the preferred route	___	W	___	S	___	N
- knowledge of ATC, and breakthrough doses	___	W	___	S	___	N
- knowledge of drug availability and cost	___	W	___	S	___	N
- knowledge of pain and symptoms in last hours of life	___	W	___	S	___	N
- conduct a comprehensive assessment of symptoms	___	W	___	S	___	N
- use appropriate assessment tools for symptom	___	W	___	S	___	N
- collaborate with person and team develop care plan	___	W	___	S	___	N
- recognize and anticipates common emergencies	___	W	___	S	___	N
- assist person to maintain functional capacity, control	___	W	___	S	___	N
- inform person how to access services 24 hours/day	___	W	___	S	___	N
- modified plan of care to address socioeconomic factors	___	W	___	S	___	N
- assess person's support system to be at home	___	W	___	S	___	N
- assess and respond to environmental safety risks	___	W	___	S	___	N
- provide information i.e. funeral preparation	___	W	___	S	___	N
- participate in advanced care-planning (DNR)	___	W	___	S	___	N
- assume a leadership role with interdisciplinary team	___	W	___	S	___	N
- facilitate transfer to different level of care setting	___	W	___	S	___	N
- facilitate for pronouncement, notification of death	___	W	___	S	___	N
- facilitate transition into bereavement	___	W	___	S	___	N
- advocate the rights of person i.e. vulnerability	___	W	___	S	___	N
- assist person in contacting relevant legal help	___	W	___	S	___	N
- recognize the need for increased services	___	W	___	S	___	N
- educate public on end-of-life issues	___	W	___	S	___	N
- advocate for policy related to end-of-life care	___	W	___	S	___	N

Please comment:

b. What education preparation is needed to support palliative care nurses for this standard?

c. What is the best education method to deliver continuing education for this standard?

Standard V: Finding Meaning-the hospice palliative care nurse assists the person and family to find meaning in their life and their experience of illness.

As a palliative care nurse how well prepared do you feel to help the person and family make sense of their situation that involves focusing on living and making the best of the situation by offering hope, as well as acknowledging and talking about death?

Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- | | | | |
|---|-------|-------|-------|
| - assist the person to feel balance with self and others | ___ W | ___ S | ___ N |
| - promote dignity and integrity | ___ W | ___ S | ___ N |
| - serving as a catalyst to finding meaning and hope | ___ W | ___ S | ___ N |
| - demonstrate in-depth knowledge of hope | ___ W | ___ S | ___ N |
| - assist the person to maintain a sense of control | ___ W | ___ S | ___ N |
| - assist person to manage emotional response to illness | ___ W | ___ S | ___ N |
| - support person to cope with uncertainty to illness | ___ W | ___ S | ___ N |
| - assist the person to clarify beliefs and values | ___ W | ___ S | ___ N |
| - assist the person to have access to resources for spiritual needs | ___ W | ___ S | ___ N |
| - realizing hope is constantly changing and is unique to person | ___ W | ___ S | ___ N |

Please comment:

b. What education preparation is needed to support palliative care nurses for this standard?

c. What is the best education method to deliver continuing education for this standard?

Standard V1: Preserving Integrity- the hospice palliative care nurse preserves the integrity of self, person and family (person shall mean person and family).

As a palliative care nurse how well prepared do you feel to maintain self-worth and self-esteem in order to continue effective functioning by learning to give and receive, grieve, put aside personal agendas, replenish oneself and stay healthy, while supporting the person and family through all the above mentioned standards of practice?

Yes _____ No _____ Sometimes _____ Unsure _____

For each item listed below please identify, whether you are: W-well-prepared, S-somewhat prepared, N-not prepared (person shall mean person and family).

- recognizes signs of stress that lead to self-exhaustion _____W _____S _____N
- identifies strategies for dealing with stress _____W _____S _____N
- aware of the evolution of worldwide palliative care movement _____W _____S _____N
- knowledge of current principles and practices of palliative care _____W _____S _____N
- identifies personal values, beliefs, and reactions to life, death, spirituality, culture, ethnicity, and religion _____W _____S _____N
- acknowledges personal values/beliefs influence practice _____W _____S _____N
- recognizes personal values/beliefs may interfere provision of care _____W _____S _____N
- demonstrates value of self by practicing self-care _____W _____S _____N
- recognizes measures to cope with multiple losses _____W _____S _____N
- balances self-care needs with complexities of dying and death _____W _____S _____N
- participates in ongoing education related to palliative nursing _____W _____S _____N
- participates in research activities appropriate to practice _____W _____S _____N
- adheres to national and provincial legislation policy/procedures _____W _____S _____N
- integrates CHPC standards into practice _____W _____S _____N
- identifies strategies to resolve ethical concerns related to EOL _____W _____S _____N
- provides comprehensive, compassionate, coordinated EOL care _____W _____S _____N
- integrates palliative care as a health promotion activity _____W _____S _____N
- supports family caregivers in practicing self care _____W _____S _____N
- recognizes signs of stress that lead to family caregiver exhaustion _____W _____S _____N

Please comment:

Appendix D

**HOSPICE PALLIATIVE CARE
NURSING STANDARDS OF
PRACTICE**

“This work is dedicated to those persons and families who, through their suffering and loss, have motivated us to improve our knowledge, skills and understanding in order to bring greater peace and comfort to those who have entrusted and who will entrust their care to us in the future”

CHPCA Nursing Standards Committee

FEBRUARY 2002

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The Canadian Hospice Palliative Care Nursing Standards Committee wish to express appreciation to all nurses from across the country who reviewed the standards and provided feedback and to Janet Carver, Nova Scotia's Palliative Care Norms of Practice Champion, who assisted the committee in revising the standards.

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INTRODUCTION

Palliative Care, according to the World Health Organization, is the “active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for persons and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with active treatment” (WHO, 1990). The Canadian Hospice Palliative Care Association (CPCA, 1995) broadened the definition of palliative care to incorporate, “the combination of active and compassionate therapies intended to comfort and support individuals and families who are living with, or dying from, a progressive life-threatening illness, or are bereaved.”

Palliative care:

- affirms life and regards dying as a normal process;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of person care;
- offers a support system to help persons live as actively as possible until death;
- offers a support system to help the family cope during the person's illness and in their own bereavement.

At some time, in some way, everyone will face the end of life. Those working in palliative care share a common hope, that when the end of life comes to us or to a loved one, it will be peaceful and free of pain, surrounded by those we love, feeling cared for and safe.

The assessment and management of pain and other symptoms associated with advanced illnesses has improved. Despite these advances the burden of suffering for Canadians remains quite high with a small number of Canadians having access to integrated and interdisciplinary palliative care.

More than 650 programs and services in the hospice palliative care network in Canada are providing care (CHPCA, 2001). Since the first programs began in 1974, thousands of Canadians have been helped to live fully during the last stages of their lives. Hospice palliative care nurses have been and still remain committed to providing quality end of life care to persons and their families. The emphasis of care is on the “whole person”

with symptom management as a well-recognised and integral part of hospice palliative care service delivery.

The person and family are identified as the unit of care, emphasizing their physical, emotional, psychosocial and spiritual needs. This practice is accomplished through an interdisciplinary team approach that provides comprehensive, coordinated and compassionate care in all care settings.

In 1993, a special interest group for hospice palliative care nurses met in Winnipeg for the first time, establishing a formal network that met at subsequent national and international palliative care conferences. The purpose of these meetings was to further develop hospice palliative care nursing in Canada. The goal of the network was to establish a national voice, which would help to identify, address, and advocate for recognition of hospice palliative care nursing as a specialty requiring advanced knowledge and clinical skills. The development of nursing standards in conjunction with the Canadian Nurses Association (CNA) and CHPCA Standards of Practice will serve as the basis of hospice palliative care nursing certification in Canada.

HISTORY OF HOSPICE PALLIATIVE CARE NURSING IN CANADA

The role of the nurse has been an integral component of the modern hospice palliative care movement since its inception in Canada in the 1970's. Influenced by the development of hospice care at St. Christopher's in England, the first palliative care services were opened November 1974 at St. Boniface Hospital, Winnipeg, Manitoba closely followed by the Royal Victoria Hospital, Montreal, Quebec in January, 1975. Since that time, hospice palliative nursing care has been developed and continues to be provided in a multitude of settings through integrated and specialized palliative care services. Improving care for persons and families is contingent upon changing systems of care. Nursing has a tremendous opportunity to influence change in current systems of care.

The Canadian Hospice Palliative Care Association (CHPCA) is the only national voice of hospice palliative care. Founded in 1993, it is a charitable non-profit association. The mission is to lead the pursuit of excellence in care for persons approaching end of life so that the burdens of suffering, loneliness and grief are lessened.

CHPCA strives to achieve its' mission through:

- Collaboration and representation
- Increased awareness, knowledge and skills related to hospice palliative care of the public, health care providers and volunteers
- Development of national standards of practice for hospice palliative care in Canada
- Support research on hospice palliative care
- Advocacy for improved hospice palliative care policy, resource allocation and support for caregivers

CHPCA has a national board of directors composed of 11-provincial/territorial hospice palliative care associations and 5 members at large. The fast growing membership includes more than 2200 nurses, physicians, health care managers, counsellors, social workers, volunteers and family members in Canada and abroad. The members serve thousands of Canadians and their families facing life threatening illness and bereavement. The national office is in Ottawa.

The CHPCA vision is to ensure that all Canadians have access to compassionate end of life care. Each year, more than 220,000 Canadians die and more than 1,000,000 Canadians are affected by the death of a loved one. It is estimated that only 5% of these Canadians have access to hospice palliative care services. CPCA wants all Canadians to have access to optimal care.

The current CHPCA consensus building process (2001) regarding standards (norms) of practice has guided the development of hospice palliative care nursing standards.

VISION

All persons and their families living with and dying from advanced illness will have access to nurses who provide knowledgeable and compassionate care to lessen the burden of suffering and improve the quality of living and dying.

MISSION

Hospice palliative care nurses bring specialized knowledge, skills and attitudes to the delivery of comprehensive, coordinated and compassionate care to all persons and families living with advanced illness. The focus is on quality of life throughout the illness continuum, dying, and bereavement. Care is provided in the setting that the person and family choose. Hospice palliative care nursing has a commitment to public and professional education, leadership, research and advocacy in caring for the person and family living with advanced illness.

PURPOSE

The purpose of hospice palliative care nursing standards in Canada is to:

- Define the standard of nursing care that can be expected by all Canadians who are living with and dying from advanced illness.
- Establish requisite knowledge for the nursing care of persons and families with advanced illness.
- Support on-going development of hospice palliative care nursing.
- Promote hospice palliative care nursing as a specialty.
- Serve as a foundation for the development of certification in hospice palliative care nursing.

PHILOSOPHICAL BELIEFS

Fawcett (1984) found a consensus in the nursing literature that identifies person, environment, health, and nursing as the fundamental units which are of the greatest importance to nursing.

The philosophical beliefs of hospice palliative care nursing are organized below according to these fundamental units. These beliefs and the Code of Ethics for Registered Nurses (1999) provide the basis of the nursing framework and the care provided by the hospice palliative care nurse.

Person

“You matter because you are you and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die.” (Saunders, 1976)

The hospice palliative care nurse believes:

- A dignified and peaceful death is the right of all persons.
- In the intrinsic value of each person as an autonomous and unique individual.
- The person and their family, living with advanced illness, are the unit of care.
- The person includes individuals from all ages and stages across the lifespan, recognizing their unique physical, emotional, social and spiritual needs.
- Hospice palliative care services should be available to all persons regardless of their age, gender, national and ethnic origin, geographical location, race, color, language, creed, religion, sexual orientation, diagnosis, disability, availability of a primary caregiver, ability to pay, criminal conviction, and family status.
- The person and family have the right to make informed decisions about all aspects of care, respecting the level of participation desired by the person and family.

Environment

The hospice palliative care nurse believes:

- Care should be provided, as much as possible, in the setting chosen by the person and family.
- Care should be provided at the primary, secondary, and tertiary levels, in the community, acute care, and long term/continuing care settings in urban, rural and remote areas. Community care settings include local hospitals, hospices, homes, lodges, prisons, group homes, rehabilitation centers, and specialized facilities such as psychiatric facilities and cancer centers.
- Care is best provided through the collaborative practice of members of an interdisciplinary team to meet the physical, emotional, social and spiritual needs of the person and their family living with advanced illness.

- Care spans the continuum from diagnosis until death of the person and includes the bereavement period for the family.

Health

The hospice palliative care nurse believes:

- Health is a state of complete physical, mental, and social well being and not merely the absence of disease or infirmity (WHO, 1990).
- In the value of life and that death is a natural process.
- Health for the person with advanced illness is a relative and dynamic state with the person experiencing varying states of wellness until the moment of death.
- Each person and/or family defines their quality of life.
- Facing death may be a personal or spiritual growth experience for each person.
- Health promotion, in the setting of advanced illness, relates to quality of life and involves assisting persons to achieve their optimum state of health and well-being during illness and in the natural process of dying.

Hospice Palliative Care Nursing

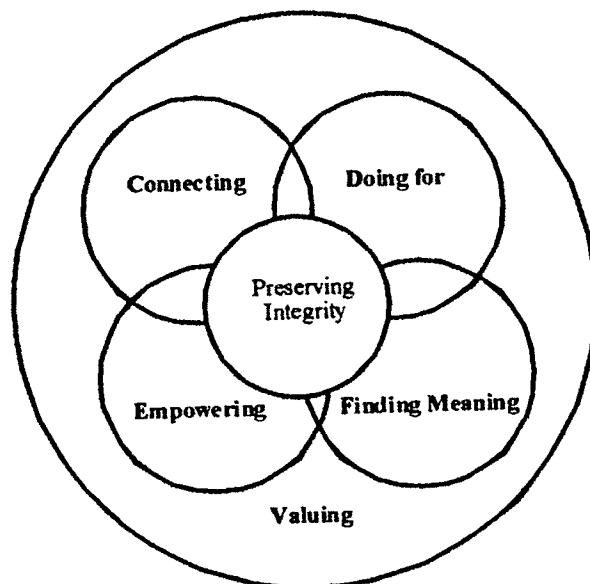
The hospice palliative care nurse believes:

- Nurses have a unique and primary responsibility for advocating for the right of persons to maintain their quality of life for as long as possible and to experience a dignified and peaceful death.
- Exemplary care is provided to persons and their families living with advanced illness through the therapeutic relationship.
- Care is guided by best practice and/or is evidence-based.
- Care respects the dignity and integrity of the person and family.
- Hospice palliative care nursing provides comprehensive, coordinated, compassionate whole person care including the physical, emotional, social and spiritual domains.
- Specialized knowledge, skill, and attitude are integral components to providing comfort and supportive care to persons and their families living with advanced illness.
- The unique body of knowledge of hospice palliative care nursing practice includes pain and symptom management, psychosocial support, and grief and bereavement.
- Hospice palliative care nursing includes all areas of practice: clinical, education, administration, research and advocacy.
- The ethical principles of autonomy, beneficence, non-maleficent, justice, truth telling and confidentiality are integrated into the provision of care and program development.
- Education, research and advocacy for the development and maintenance of public policy, palliative care standards, and resources are essential to improve the delivery of palliative care.
- Hospice palliative nursing care is active in the application of knowledge, skills and attitudes and is not passive in nature.

FRAMEWORK FOR HOSPICE PALLIATIVE CARE NURSING

The Supportive Care Model (Davies & Oberle, 1990) was adapted to clearly reflect hospice palliative care nursing practice and then adopted as the framework for hospice palliative care nursing. The original model was developed through analysis of the care provided by a supportive care nurse who worked in a Pain and Symptom Control Clinic. The analysis identified six interwoven dimensions that make up the clinical portion of the nursing role in palliative care. The six dimensions are: valuing, connecting, empowering, doing for, finding meaning, and preserving integrity (Davies & Oberle, 1990). These dimensions are depicted below as interconnected circles with "valuing" as the outer circle, which underlies all nursing practice and "preserving integrity" as the centre circle which is the heart of hospice palliative care nursing practice. Although intertwined, each dimension is described separately.

Figure 1. Supportive role of the nurse in palliative care-dimensions of care.



Valuing

"Valuing" is the dimension that provides the context for supportive care (Oberle & Davies, 1992). "Valuing" includes a global component which involves respect for the worth of all humans, as well as a particular component which involves respect for a particular individual based on recognition of their characteristics and abilities. "Valuing" is primarily an attitude rather than an action.

Connecting

The dimension of "connecting" involves making a connection with the person and family, sustaining the connection and then breaking the connection. Davies and Oberle (1990) suggest that some degree of connecting must occur before one can empower, but the connection must also be maintained throughout the process. In making the connection the nurse would begin to build a trusting relationship by taking time to get to know the

person/family, establishing credentials, explaining the roles of the team members, getting a baseline assessment, explaining how to contact the nurse, finding a common bond and establishing rapport with the person and family, and communicating effectively. In order to sustain the connection the nurse would be available and spend time with the family, maintain confidentiality and privacy, and give of self. Nurses continue to provide bereavement support to families after the death of a person but over time the connection is broken.

Empowering

The dimension of "empowering" involves helping the person and family to uncover and build on their own strengths (Oberle & Davies, 1992). The components of "empowering" include assessing the family, assessing and supporting the person and family's coping style, assisting with decision making and supporting choices made by the family, assisting the family to deal with ethical dilemmas, allowing the family to vent and defuse frustrations, assisting in healing relationships, and giving information on all aspects of care.

Doing for

The fourth dimension in the Supportive Care Model is "doing for" which is entwined with "empowering". The goal of "doing for" is to free up the person and family to focus energy in the areas that are most empowering for them. The key is in finding a balance between "doing for" and "empowering". This balance can be accomplished by collaborating with the family to identify expectations and goals, and develop a plan of care, and by maintaining a belief in the family's strength and ability to ultimately find their own solutions.

The actions taken in "doing for" include pain and symptom management, co-ordination of care, and advocating for the rights of the person and family (Davies & Oberle, 1990). In providing pain and symptom management the nurse conducts a comprehensive assessment of pain and other symptoms using valid and developmentally appropriate tools. The nurse collaborates with the person, family and interdisciplinary team to develop and implement a plan of care to manage pain and other symptoms, with particular attention to anticipating symptoms and/or side effects and managing symptoms in the final hours of life. Co-ordination of care involves collaborating with and taking a leadership role in the interdisciplinary team, facilitating communication to smooth transitions between different care providers or care settings, assisting the person and family to access resources as needed, and facilitating the necessary procedures that occur at the time of death (pronouncement, transportation of the deceased, support for family, etc.). Advocating for the rights of the person and family includes activities on a global level to educate others and improve services and resources available to the person and family. Other activities include advocating for the rights of a specific person and family to obtain necessary equipment or services, to have a voice as part of an interdisciplinary team and to deal with legal issues.

Finding meaning

The dimension of "finding meaning" involves helping the person and family make sense of their situation which is "strength-giving, and therefore empowering" (Davies & Oberle, 1990, p. 92). Davies and Oberle (1990) suggest "finding meaning" involves focussing on living and making the best of the situation by offering hope, as well as acknowledging and talking about death. A major component of this dimension is care of the person and family's spiritual needs.

Preserving integrity

The final dimension, which is the core of the Supportive Care Model, is "preserving integrity". This dimension refers to both the integrity of the nurse and the integrity of the person or family (Oberle & Davies, 1993). For the nurse, this dimension includes the ability to maintain self-worth and self-esteem in order to continue effective functioning (Davies & Oberle, 1990). The integrity of the nurse is preserved by providing support through "connecting", "empowering", "finding meaning", and "doing for" but there must also be some replenishing and sustaining activities on the part of the nurse to maintain the energy to carry out these four dimensions. Zerwekh (1995) suggests that the nurse must first take care of self by learning to giving and receiving, learning to grieve, putting aside personal agendas, replenishing oneself, and staying healthy. Other activities that support the nurse's ability to provide care include reflecting on personal values and beliefs, maintaining a current knowledge base in hospice palliative care through education and research activities, and by dealing with ethical issues as they arise.

Preserving the integrity of the person and family is considered the goal of nursing care and is accomplished by providing support through all dimensions of the Supportive Care Model (Oberle & Davies, 1993). For example, if a nurse only focuses on the dimension of "doing for" the family, other psychosocial and spiritual needs, which are met primarily through the other dimensions, are dismissed. This dismissal may threaten the integrity of the person and family.

CANADIAN STANDARDS OF HOSPICE PALLIATIVE CARE NURSING

The six dimensions of the Supportive Care Model provide the framework around which the Canadian Standards of Hospice Palliative Care Nursing have been developed. These nursing standards are reflective of the CPCA 2001 Proposed Norms of Practice for hospice palliative care, but are a specific guide for nursing practice which clearly identifies the role of the hospice palliative care nurse as a member of the interdisciplinary team.

Standard I - Valuing

The hospice palliative care nurse believes in the intrinsic worth of others, the value of life and that death is a natural process.

The hospice palliative care nurse:

- Advocates that all persons and families with advanced illness have access to available resources.
- Provides care in a nonjudgmental and nondiscriminatory manner that is sensitive to persons and families diversity.
- Empowers persons and families to be active participants in their plan of care.
- Acknowledges whole person care with an understanding of the individual's unique characteristics and abilities.
- Assists the person to find meaning in their unique life and illness experience.
- Assists the person to achieve the best quality of life as defined by the person.
- Acknowledges that death is natural life progression.
- Recognizes and preserves the integrity of self and others.
- Collaborates in creating a social change in the way society views death and dying.

Standard II: Connecting

The hospice palliative care nurse establishes a therapeutic connection (relationship) with the person and their family through making, sustaining and closing the relationship.

Making the Connection

The hospice palliative care nurse:

- Recognizes personal attitudes, feelings, and values regarding death.
- Creates an atmosphere to facilitate trust.
- Seeks to understand the person and family's perspective, their expectations and needs.
- Communicates in a skillful and sensitive manner.
- Listens actively as an integral part of communication.
- Explains the role of nursing and other interdisciplinary team members.
- Assesses the influence of cultural and spiritual values, beliefs, traditions, lifeway patterns of the person and family on their illness experience.
- Adapts to the unique needs of each person and family.

Sustaining the Connection

The hospice palliative care nurse:

- Uses skills in verbal and non-verbal communication, listening and presence.
- Responds to the expressed expectations and needs of the person and family.
- Demonstrates a sense of true presence by continual, unconditional acceptance and tolerance.
- Encourages and supports the expression of feelings, perceptions and fears.
- Respects confidentiality and privacy.

- Respects the persons and family's specific care requests.
- Respects the different emotional needs of the person and their family.
- Remains vigilant with respect to maintaining professional boundaries.
- Demonstrates a comfort level in communicating with the person and family about issues related to death and dying.
- Initiates discussions with the person and family about issues related to meaning, implications of diagnosis and prognosis, dying and death.
- Responds in a timely, sensitive, honest manner to the person and family's questions and concerns.
- Helps persons and families to establish priorities.
- Reviews regularly the disease progression, goals of care and treatment with the person, family and team and adjusts plan accordingly.

Closing the Connection

The hospice palliative care nurse:

- Assists the person and family to prepare for the dying process and manage the end of life event.
- Demonstrates in-depth knowledge of grief and bereavement care.
- Assists the family in the process of grief and bereavement.
- Recognizes the need for self-closure and healing.
- Prepares the family for the eventual closure of the nurse-family relationship.

Standard III – Empowering

The hospice palliative care nurse provides care in a manner that is empowering for the person and family.

The hospice palliative care nurse:

- Identifies priorities for care based on the person and family's perspective.

- Assists the person and family to identify and build on their own strengths.
- Assists the person with advanced illness to address sensitive, personal issues related to sexuality and intimacy.
- Demonstrates knowledge of the broad range of emotions associated with changing body image and self-esteem.
- Establishes a plan of care in collaboration with the person and family.
- Assesses the person and family's learning needs and style.
- Respects the person and family's desire to seek therapies not offered in the conventional health care system.
- Assists the person and family to gather relevant information about the costs, risks and benefits of treatment and end-of-life care in order to make informed decisions.
- Supports informed choices that the person and family have made including withholding treatment, withdrawing life-sustaining therapies.
- Identifies and supports the person and family's coping style.
- Demonstrates awareness of techniques of conflict resolution.
- Collaborates with the person and family to address ethical dilemmas.
- Understands the influence of family dynamics on the illness continuum.
- Assists the person and family to recognize and respect each other's points of views.
- Assists the person and family in memory making and reminiscing.
- Provides relevant information appropriate to the developmental level of the person and family such as:
 - Disease process and progression of advanced illness.
 - Options for care and available resources and services.
 - Basic pain and symptom assessment and management.

- Physical care and emotional and spiritual support of the person during the progression of the advanced illness.
- Medications: action, side effects, administration.
- Treatments: purpose, benefits, adverse effects.
- Emergencies and complications: spinal cord compression, superior vena cava syndrome, cardiac tamponade, hemorrhage, seizures, hypercalcemia, opioid toxicity, and delirium.
- Grief and bereavement: type of grief responses (anticipatory and normal), how to cope with grief, potential reactions of family and friends (including children).
- The dying process: signs and symptoms of imminent death, coping strategies and how to provide support and comfort during the final hours.

Standard IV – Doing for

The hospice palliative care nurse provides care based on best practice and/or evidence-based practice in the following areas: pain and symptom management, coordination of care and advocacy.

Pain and symptom management

The hospice palliative care nurse incorporates accepted principles of pain management into his/her delivery of care.

The hospice palliative nurse:

- Identifies the multi dimensional factors that influence the person's 'total' pain experience.
- Recognizes that each person's experience of pain is unique.
- Advocates for appropriate pain management measures.
- Collaborates with person, family and team to develop an effective plan to manage pain through the use of pharmacological interventions.

- Acknowledges the person and family's potential need to seek other therapies for pain management, within the domain of Complementary and Alternative Medicine (CAM).
- Supports the belief that CAM can coexist with mainstream/traditional medical therapies as part of the plan of care.
- Demonstrates knowledge of the special considerations of children and the elderly.
- Demonstrates an understanding of the various types of pain and pain syndromes and their importance in the effective management of pain.
- Demonstrates the knowledge of the pathophysiology of pain.
- Uses an evidence-based model as a standard for pain management (i.e. WHO ladder)
- Identifies the barriers and myths related to opioid use (e.g. addiction).
- Demonstrates knowledge of opioids, which are the basis of pain management.
- Demonstrates knowledge of the side effects of opioids and their management.
- Teaches the person and family the principles of pain management.

Assessment

- Conducts a comprehensive pain assessment.
- Assesses tolerance of pain, intervenes as required for persons and family who are reluctant/unable to acknowledge their pain.
- Uses age appropriate, valid assessment tools in initial pain assessment and for ongoing evaluation.
- Assesses for and implements appropriate measures to treat side effects or complications (e.g. opioid toxicity, myoclonus, urinary retention, delirium).
- Recognizes the symptoms that may require medical intervention.
- Anticipates and develops measures that address potential side effects (e.g. nausea, vomiting and constipation).
- Demonstrates knowledge of indications for opioid rotation

- Assesses for and intervenes in psychosocial and spiritual issues related to pain.
- Ascertains and documents the CAM therapies the client is using

Management

- Acknowledges the critical need for attention to special populations such as children, the elderly and the poor.
- Collaboratively develops an effective plan to manage pain safely through use of non- pharmacological interventions considering complementary/alternative therapies.
- Reinforces with the client and family the importance of accessing accurate information to assist in their decision-making of choosing a CAM therapy
- Encourages client and family to keep the health care team informed about the use of any CAM therapies
- Administers the medications and or techniques that are appropriate to the severity and specific types of pain.
- Monitors on a regular basis the amount of breakthrough medications needed in 24 hours.
- Administers medications in doses sufficient to control the pain and in intervals appropriate to the medication duration of action.
- Demonstrates knowledge of equianalgesic conversions when medications are changed.
- Demonstrates knowledge regarding the combined use of opioid and adjuvant medications for more effective analgesia.
- Demonstrates understanding of the pharmacological and physiological use of adjuvant medications in managing pain in advanced disease (e.g. non-steroidal anti-inflammatory drugs (NSAID's), corticosteroids, anticonvulsants, anti-depressants, antipsychotics).
- Enhances medication delivery by recognizing the use of the oral route as the preferred method of administration.
- Demonstrates knowledge of pain management philosophy by administering medications around the clock (ATC), at regular intervals, and by providing breakthrough dose medication.

- Demonstrates knowledge of opioid rotation.
- Demonstrates knowledge of drug availability and costs.
- Demonstrates knowledge of drug interactions and compatibility with other medications.
- Evaluates the effect of the medication and/or side effects and revises plan accordingly.
- Demonstrates knowledge of the unique pain and symptom management strategies in the last hours of life.

The hospice palliative care nurse follows the principles of symptom management.

The hospice palliative care nurse:

- Conducts a comprehensive assessment of symptoms.
- Uses age appropriate valid assessment tools in initial symptom assessment and for ongoing evaluation.
- Collaborates with the person and interdisciplinary team to develop a symptom management plan.
- Demonstrates knowledge to assess and alleviate to the greatest extent possible the following common symptoms:
 - Cardio-respiratory: dyspnea, cough, edema, hiccoughs, congestion
 - Gastrointestinal: candidiasis, mucositis, nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, ascites, dehydration, incontinence, jaundice
 - General: anorexia, cachexia, fatigue, sleep disturbances, weakness, bleeding, odour, pruritus, bladder spasms, urinary retention, skin breakdown, seizures, myoclonus
 - Cognitive: agitation, delirium, confusion, depression, hallucinations, paranoia
 - Psychosocial and Spiritual: anxiety, fear, anger, grief
- Manages the symptoms in the final hours of life (e.g., mouth care, anxiety and insomnia, myoclonus, seizures, lymphoedema and decubitus ulcers, excess terminal respiratory secretions).

- Anticipates and recognizes signs and symptoms for common emergencies: spinal cord compression, superior vena cava syndrome, cardiac tamponade, hemorrhage, seizures, hypercalcemia, opioid toxicity, and delirium.
- Demonstrates knowledge of the medical interventions appropriate to common emergencies and advocates for a timely medical response.

Coordination of care

The hospice palliative care nurse:

- Assists to maintain the person's functional capacity and control and independence.
- Informs person and family how to access services 24 hours/day.
- Modifies plan of care to accommodate socioeconomic factors resulting from unique issues of advanced illness.
- Assesses and monitors the family's willingness, availability and ability to support the person in the home environment throughout the continuum of the person's illness.
- Assesses and responds to environmental safety risks.
- Assesses the appropriateness of the home environment in preparation for end-of-life care and/or home death.
- Teaches regarding safe disposal of supplies/equipment (e.g., opioids, syringes, needles).
- Monitors safe disposal of supplies/equipment.
- Provides information regarding funeral practices/preparation.
- Facilitates effective communication between person, family and care providers.
- Makes referrals to appropriate interdisciplinary team members.
- Participates in advanced care planning (e.g., advance directives, life support, DNR status).
- Assumes a leadership role in coordinating the work of the interdisciplinary team.

- Promotes continuity of care and services.
- Arranges for medical equipment, supplies, or medications.
- Facilitates and coordinates transfer to a different level of care or care setting.
- Coordinates and participates in person and family conferences.
- Initiates and participates in interdisciplinary team conferences.
- Facilitates arrangements for pronouncement, notification of death or transportation of deceased.
- Facilitates transition into bereavement services.

Advocacy

The hospice palliative care nurse:

- Advocates and defends the rights of the person and family recognizing their vulnerability.
- Intercedes on behalf of person and family with appropriate services whenever necessary.
- Assists the person and family in identifying and dealing with relevant legal issues (e.g., personal and advanced directives, power of attorney, proxy).
- Recognizes the need for increased services.
- Encourages person and family role in interdisciplinary team decisions.
- Educates the public and other health care providers on end-of-life issues and hospice palliative care, so that all persons explicitly benefit from this specialized knowledge.
- Advocates in the development of health care policy related to hospice palliative care.

Standard V – Finding meaning

The hospice palliative care nurse assists the person and family to find meaning in their life and their experience of illness.

The hospice palliative care nurse:

- Assists the person to feel balance and connection with self, others, all life or higher power as appropriate.
- Promotes dignity and integrity.
- Is a catalyst to finding meaning and hope.
- Demonstrates in-depth knowledge of the concept of hope.
- Assists the person and family to maintain a sense of control.
- Assists the person and the family to manage the emotional response to the illness experience.
- Supports the person and family in coping with the uncertainty related to the illness.
- Assists the persons and families to clarify beliefs and values as appropriate.
- Assists the person and families to have access to the appropriate resources to meet and address their spiritual needs.
- Assists the person and family to maintain hope for the future acknowledging that the focus of hope is constantly changing and is unique to the individual.

Standard VI - Preserving Integrity

The hospice palliative care nurse preserves the integrity of self, person and family.

Self

The hospice palliative care nurse:

- Recognizes signs of stress that lead to self-exhaustion and identifies strategies for dealing with stress.
- Demonstrates in-depth knowledge of the historical evolution of the modern hospice palliative care movement worldwide.
- Demonstrates knowledge of the current principles and practices of palliative care.
- Identifies personal values, beliefs, and reactions related to life, death, spirituality, culture, ethnicity, and religion.
- Acknowledges how personal values and beliefs impact/influence practice.
- Recognizes personal values and beliefs and ensures they do not interfere with the provision of care.
- Demonstrates value of self by practicing self-care.
- Recognizes and takes appropriate measures to cope with multiple losses and grief reactions.
- Balances own self-care needs with the complexities and intensities of dying and death.
- Participates in ongoing educational activities related to hospice palliative nursing and hospice palliative care.
- Applies knowledge gained through education about hospice palliative care by making appropriate changes in practice.
- Participates in research activities appropriate to the individual's position, education and practice environment.

- Practices in a manner that reflects the Code of Ethics for nursing.
- Adheres to national and provincial legislation as well as agency policies and procedures.
- Integrates the CPCA standards into practice.
- Engages in discussions and identifies strategies to resolve ethical concerns related to end of life.

Person and family

The hospice palliative care nurse:

- Provides comprehensive, compassionate, coordinated care.
- Recognizes that even with the provision of excellent palliative care, the loss of a loved one creates intense grief.
- Integrates palliative care as a health promotion activity at the person, family and community level.
- Supports the family caregiver(s) in practicing self care activities to prevent a deterioration of health.
- Recognizes signs of stress that lead to family caregiver exhaustion and assists the family to identify strategies for dealing with stress.

GLOSSARY

Advanced directives: A patient's formal or informal instructions concerning expectations of care and choice of treatment options in response to potential illnesses or conditions (legal connotations vary by jurisdiction; includes a living will)

Advanced illness: An illness that is life threatening and likely to be progressive.

Advocacy: The act of working on behalf of the person and their family in order to promote their autonomy.

Bereavement: State of having suffered a significant loss through death.

Caregiver: Anyone who provides care.

Formal caregivers are members of an organizational and accountable to defined norms of conduct and practice. They may be professionals, support workers, or volunteers. They are sometimes called "providers".

Informal caregivers are not members of an organization. They have no formal training, and are not accountable to norms of conduct or practice. They may be family members or friends.

Complementary and Alternative Medicine (CAM): Complementary or alternative therapies are defined as those health care practices that are not part of the mainstream system for managing health and disease.

Comprehensive coordinated care: Is service that integrates key dimensions in palliative care related to pain and symptom management, supportive care and grief and bereavement care. The care is guided by an identified interdisciplinary team member who assumes lead in linking the services and the caregivers (both formal and informal) across all care settings.

Family: Those closest to the person in knowledge, care and affection. May include:

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

The person defines who will be involved in his/her care and/or present at the bedside.

Grief: Sorrow experienced in anticipation of, during and after a loss.

Interdisciplinary team: A team of caregivers who work together to develop and implement a plan of care. Membership varies depending on the services required to address the identified expectations and needs.

Lifeways: Are established patterns within the family unit that illustrates their valuing of certain rituals, traditions and beliefs.

Pain :An unpleasant sensory and emotional experience that is primarily associated with tissue damage or described in terms of tissue damage, or both. (International Association for the Study of Pain – refer to www.halcyon.com/iap/dict.html.)

Person: The individual living with advanced, progressive illness.

Quality of life: Well being as defined by the person living with advanced illness. It is the gold standard for palliative care.

Setting: The location where care is provided. Settings for hospice palliative care may include the person's home, an acute, chronic, or long-term care facility, a nursing home/skilled nursing facility, a hospice or palliative care unit or freestanding facility, a jail or prison, the street, etc.

Spirituality: The transcendent dimension of a person's life. May be described in terms of inspiration, meaning, and/or value. An organized religion may be part of an individual's spiritual experience.

“Total Pain”: Suffering related to, and the result of, the person's physical, psychological, social, spiritual and practical state.

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