

The Principles and Practice of Palliative Care Nursing and Palliative Care Competencies for Canadian Nurses (September, 2009)

Brenda Jacono, Cape Breton University (Chair), Beryl Cable-Williams, Fleming College, ON, Cathy Foster, Brandon University, MB, Mitzi Grace Mitchell, York University, ON, Mireille Lavoie, Université Laval, QC, Holly Richardson, Dalhousie University, NS, Heather Jewers, St. Francis Xavier University, NS, Lynne Young, University of Victoria, BC, Sharon Baxter, CHPCA

Preamble

Purpose of the Competencies

Nurses, regardless of the setting they work in, will encounter people who require palliative or end-of-life care. Despite the fact that most nurses will bear witness to this event in their everyday work lives, many remain ill prepared to provide support to dying persons and their families (Halliday & Boughton, 2008; Mallory, 2003). According to the Honourable Sharon Carstairs in her report of the subcommittee to update *Of Life and Death* of the Standing Senate Committee on Social Affairs, Science and Technology, “appropriate education and training are crucial for all members of the interdisciplinary end-of-life care team. [However], few universities or community colleges in Canada offer palliative care training programs” (2000, p. 8-9). This latter statement is consistent with the literature throughout North America and abroad in which historically nursing education has been found to be lacking in end-of-life learning experiences (Caly & Tamlyn, 1984; Downe-Wamboldt & Tamlyn, 1997; Ferrell et al, 2005; Mallory, 2003; Mok, Lee, & Wong, 2002; O’Gorman, 1998). The most recent findings from an unpublished survey (conducted by the CASN Task Force on Palliative Care) of the 91 nursing schools in Canada indicate that palliative and end-of-life care (PEOLC) education is a required course in only 4% of the responding schools (n=49) (CASN, 2007). Furthermore, only 17% of the responding schools offered an elective course in PEOLC with the majority (89%) estimating that only half of their students would likely obtain the course prior to graduation. Twenty-two percent did not offer any courses in PEOLC indicating that material was integrated throughout their programs (CASN, 2007). When these results are compared with a survey conducted by Downe-Wamboldt and Tamlyn (1997), this shows very little change in the state of palliative care education in Canadian nursing schools over the past 13 years despite the reported inadequacy of preparation of nurses to deal with end-of-life issues.

A lack of palliative care education has resulted in nurses being unable to cope with the inevitability of death (O’Gorman, 1998) and may also result in nurses contributing to dying persons’ suffering due to inappropriate communication, a lack of compassion, or from nurses’ unresolved personal issues about death and dying (Mok, Lee, & Wong, 2002). Anxiety about caring for dying persons is related to students’ personal death anxiety (Austin Hurtig & Stewin, 1989; Mallory, 2003; Mok, Lee, & Wong, 2002), and such anxiety is also likely to lead to avoidance of dying persons and their families (Austin Hurtig & Stewin, 1989; Mok, Lee, &

Wong, 2002; O’Gorman, 1998). Research suggests that PEOLC education positively influences student nurses’ attitudes toward death and caring for dying persons (Mallory, 2003; Mok, Lee, & Wong), and that early introduction and extensive exploration of death issues along with practical experience is necessary in undergraduate nursing programs in order to adequately prepare nurses to provide supportive care to dying persons and their families (Halliday & Boughton, 2008). This supports the need for concentrated study within a stand-alone PEOLC course rather than an integration of material throughout the curriculum and accentuates the need for the development of competencies to guide curriculum development.

Palliative and End-of-Life Education is relevant to all health disciplines and, while three different disciplines from various academic institutions from the U.K., the U.S., and Canada report using an interdisciplinary approach to education, the majority use educators from within their own disciplines (Downe-Wamboldt & Tamlyn, 1997). This indicates an appreciation for interdisciplinary education, however, we still aspire to a more collaborative teaching and learning approach among health professional schools across Canada as indicated by the Canadian Hospice and Palliative Care Association’s Invitational Symposium on the Future of Interprofessional Education and Practice in Palliative and End-of-life Care held on October 25, 2008. In support of this endeavor, the honourable Sharon Carstairs recommended “that the federal government support the development of multi-disciplinary education and training with respect to palliative and end-of-life care and support an integrated and coordinated approach to palliative and end-of-life care across care settings” (2005, p. 29). Given the historical evidence of the lack of adequate PEOLC education in nursing, it was necessary to develop competencies that were informed by nurses to ensure they were comprehensive and relevant. While these provide a foundation for guiding PEOLC curriculum development in nursing, it is also evident that many of these competencies are relevant to other disciplines as well. With this guiding foundation, we envision working more collaboratively with other disciplines to share this work and find creative ways to teach and learn together to adequately prepare future health professionals, including nurses, for collaborative practice in the care of the dying and their families.

Definition of Palliative Care

The Canadian Hospice Palliative Care Association defines palliative care as “whole-person health care that aims to relieve suffering and improve the quality of living and dying” (retrieved September, 2009 from <http://www.chpca.net/home.html>)

Palliative care (CHPCA, 2002, p. 5):

- 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 care;
- offers a support system to help persons live as actively as possible until death; and
- offers a support system to help families cope during the person’s illness and in their own bereavement.

Palliative care is “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” (CHPCA, 2002, p. 5). Palliative care is guided by the principles of Primary Health Care and is characterized by care that is: accessible, participatory, inter-professional, health promoting, and uses appropriate technology and skill (CNA, 2005).

According to the World Health Organization (retrieved September, 2009 from <http://www.who.int/cancer/palliative/definition/en/>), “palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care: ...

- 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.”

Nurses’ Roles in Palliative Care

Professional nursing practice is based on a philosophy that nursing is interpersonal and holistic in nature. This implies that the nurse uses the nurse-patient relationship as the foundation for care in order to address the patient and family’s physiological, emotional, psychosocial, spiritual, and practical needs. The achievement of an effective nurse-patient relationship involves certain crucial attitudes and behaviours on the part of the nurse. These attitudes and behaviours allow the nurse to empathize with the patient and to be sensitive to the patient’s needs without becoming overly enmeshed in the patient’s situation.

The nurse’s role in palliative care encompasses many interconnected dimensions. These dimensions include: valuing; finding meaning; empowering; connecting; doing for; and preserving integrity of self and others (Davies & Oberle, 1990, as cited in CHPCA, 2002). While some of these dimensions are more task-oriented, others are largely attitudinal and reflect the interpersonal and holistic nature of nursing. They imply that the nurse as a professional cannot be separated from the nurse as a person, if a therapeutic nurse-patient relationship is to be achieved. Central to this is the dimension of *valuing*. The following describe the dimensions of the nurse’s role:

- *Valuing* means that the nurse has a basic belief in the inherent worth of all human beings, regardless of any particular characteristics of any one individual. Valuing allows the nurse to be able to continue to respect and provide care to the patient, even under adverse conditions (Davies & Oberle, 1990).
- *Finding meaning* means that the nurse is able to assist patients to find meaning in their situations. This includes helping patients to focus on living until they die, helping them to make the best of their situation, offering hope, encouraging reflection on their life, helping them to fulfill spiritual needs, and acknowledging death by talking openly about death when

patients and families want them to do so (Davies & Oberle, 1990).

- *Empowering* involves facilitating, encouraging, defusing, mending, and giving information. Facilitating builds individual and family strengths. The nurse facilitates by involving the patient and family in planning strategies, offering suggestions, explaining options, and providing information. Through these actions the nurse shows respect for the patient and family's right and ability to make decisions. The nurse also recognizes limitations and helps them to work toward a more positive outcome. Encouraging is when the nurse acknowledges patient and family abilities, supports choices, and encourages patients and families to do what they choose. Defusing is helping the patients or families to deal with their negative feelings and giving them permission to express them. By listening openly and not acting defensively, the nurse allows the person to ventilate their anger. Mending means the nurse helps to facilitate healing between family members by interpreting behaviours and enabling individuals to see each other's point of view. Giving information pertains to the nurse's teaching and explaining about medications, changes, and pain and other symptoms. This strengthens the patient's and family's capacity to manage for themselves (Davies & Oberle, 1990).
- *Connecting* refers to the nurse making contact with the patient and establishing a therapeutic relationship. This involves introductions, establishing credentials, explaining roles, collecting baseline information, and explaining how to contact the nurse (Davies & Oberle, 1990).
- *Doing for* is focused on the physical care of the patient. It involves controlling pain and symptoms, making arrangements such as discharge planning and helping families to access equipment, and helping with hands-on care. Team collaboration is also a component of doing for. Team collaboration involves negotiating the system on behalf of the patient and family, consulting with other team members, sharing information, serving as a liaison between various institutions and programs, mediating on behalf of the family and often explaining, encouraging and pleading for the benefit of the patient and family (Davies & Oberle, 1990).
- *Preserving own integrity* refers to the nurse's ability to maintain feelings of self-worth, self-esteem, and energy levels in the face of routine exposure to suffering, pain and loss. This involves reflecting on what the nurse regards as important and gives meaning to life and the work that the nurse is doing. It is also influenced by the nurse's evaluation of the care he/she has given to a patient and feeling that it has helped the patient. Self-awareness, being able to acknowledge his/her own feelings and reactions is also integral to preserving one's own integrity. This enables the nurse to assess whether he/she is doing the right thing for the right reason and helps him/her to maintain perspective, as well as an awareness of one's own limitations. The nurse needs to accept that he/she cannot do all and be all to everyone and know when to draw the line. Otherwise exhaustion will result (Davies & Oberle, 1990). The system needs to ensure that resources are in place to prevent nurse burnout and compassion fatigue.

Nurses' roles include active participation in clinical care, education, inter-professional collaboration, system capacity, competence in palliative care, research, and policy development. Palliative Care, guided by the Principles of Primary Health Care, would extend the nurse's role to include that of advocate. Primary health care in this context extends beyond the health care system itself to include accessibility, community care, and the social determinants of health. Nurses also play a role in supporting the family and inter-professional team. Palliative care is

central to expressing and reflecting the essence of nursing and nursing care because it encompasses spiritual, emotional, family, and other non-clinical dimensions.

Effective pain management is integral to patient safety, a quality work environment, and ethical nursing practice (Anwari, 2008; Peter & Watt-Watson, 2002; Pierce, Dalton, & Duffey, 2001; Rees, King, & Schmitz, 2009; Sabo, 2006; Safran, Miller, & Beckman, 2006). Ineffective pain management affects the overall health experience of many patients and their families, and places patients at increased risk for morbidity and mortality. In fact, “inadequate pain relief hastens death by increasing physiological stress, potentially diminishing immunocompetence, decreasing mobility, worsening proclivities toward pneumonia and thromboembolism, and increasing work of breathing and myocardial oxygen requirements. Furthermore, pain may lead to spiritual death as the individual’s quality of life is impaired” (Ferrell & Coyle, 2006, p.133). Also “ineffective pain management disrupts the relationships between nurses and their patients between nurses and physicians, and between nurses and other professionals; it is a factor that affects the quality of nurses’ work life” (Canadian Nurses’ Pain Issues Working Group, 2005, p. 1, also supported by Maher & Hemming, 2005). Thus, effective pain care is a moral imperative for palliative care nurses.

These guiding principles underpin the following requisite general and specific/core competencies for nurses caring for individuals and families who are facing the end of life. The general competencies that are described below are those required for all registered nurses and are thus expected from any nurse providing palliative and end-of-life care. The specific competencies are intended to address particular issues and needs that contribute to suffering and impact on quality of life in patients who are dying or living with advanced or life-limiting illness.

General competencies

1. Engages in relational practice, which is characterized by: skill with listening; the ability to engage in difficult conversations; the ability to *be present* with patients; responsiveness; respect for lived experience and meanings arising; appreciating patient and family choices and strengths; collaborative care and fostering dignity.
2. Demonstrates knowledge of and skill in utilizing the principles and standards of palliative and end-of-life care in a culturally relevant Canadian context.
3. Uses reflexivity in practice, reflexivity being defined as the ability to critically reflect on the values, beliefs, and assumptions underpinning culturally relevant practice and awareness of the system level influences and discourses that impact on the caring process.
4. Practices according to the CNA Code of Ethics and Standards for Nursing Practice.
5. Demonstrates intentionality in practice, intentionality being defined as the congruence between espoused knowledge, values, and beliefs and those used in practice (Doanne and Varcoe, 2005).
6. Engages in patient/family-centered care defined as a relational practice that focuses on family as defined by the patient (Doane & Varcoe, 2005).
7. Utilizes evidence-based practice, defined as an approach to decision making in which the clinician uses the best evidence available, in consultation with the patient and

family to decide upon which course of action is most appropriate.

(Retrieved April 26, 2006 from www.nhstayside.scot.nhs.uk/FoISA/Glossary.htm;
Green, 2001).

8. Shows ability to collaborate inter-professionally to address patient/family needs. Inter-professional collaboration is practice that integrates concepts and knowledge from all involved health disciplines/professions, and includes anyone who works under a formally accredited organization. It includes volunteers who are under the supervision of the organization (thus differentiating them from family members who provide care).
9. Practices advocacy defined as: “the process wherein the nurse, knowledgeable of the socio-political context, acts on behalf of the patient or the nursing profession to assure the delivery of quality nursing care and to promote professional standards of practice. The skills of advocacy include mediating, coordinating, clarifying, resolving conflict, and assisting the patient to acquire, interpret, and utilize health care information.” (Beth-El College of Nursing & Health Sciences (2001), Retrieved September 4, 2009 from http://web.uccs.edu/bethelstudenthandbook/definition_of_curriculum_terms.htm)

Specific competencies

1. Possesses self-awareness of personal attitudes, beliefs, and values about death and dying. It includes care of self, understanding one’s own needs, developing one’s own support and knowledge networks, being open to learning, and knowing how to be with suffering.
2. Exhibits skill in conducting holistic individual and family assessments, including but not limited to pain, dyspnea, nausea, vomiting, and other symptoms. This also includes assessment of psychosocial, emotional, and spiritual issues relevant to palliative and end-of-life situations.
3. Demonstrates knowledge and skill in managing pain and symptoms.
4. Possesses requisite communication skills and an ability to engage in end-of-life decision making and planning, and negotiate modes of care on an ongoing basis while being respectful of the client and remaining open to potential change.
5. Possesses knowledge of cultural and spiritual issues that impact on end-of-life care and the ability to recognize and be present with persons in their experiences of suffering.
6. Demonstrates ability to assess and attend to individual/family psychosocial and practical issues such as discharge planning for death at home, funeral arrangements, and planning for life without their loved one.
7. Possesses and applies appropriate ethical knowledge and skill in acting in the best interest of the patient and family while recognizing and attending to one’s own moral distress and dilemmas with regard to end-of life decision making.
8. Recognizes and responds to the unique end-of-life needs of special populations while assisting them to realize optimal quality of life, i.e. elders, children, those with

- cognitive impairment, those in rural and remote areas, those with chronic diseases, mental illness and addictions, and other unique and marginalized populations.
9. Demonstrates knowledge of grief and bereavement and the ability to support others.
 10. Demonstrates caring for self while supporting others in their grief and bereavement. Real compassion is uplifting and contributes to personal growth; unresolved grief causes pain, which can contribute to fatigue. The nurse recognizes his or her limitations, and issues that could contribute to emotional exhaustion.
 11. Defines the full range and continuum of palliative and end-of-life care services and the settings in which they are available (e.g. home care). Facilitates access to timely, comprehensive, high quality palliative and end-of-life care in any setting of the patient's choice (CHPCA, 2006).
 12. Has the ability to: educate and mentor patients and family members on end-of-life care needs, identify the need for respite for family members, and safely and appropriately delegate care to other caregivers (e.g. personal care workers) (CHPCA, 2006).

Lexicon of Commonly Used Terms

Ability to “be present”: Nursing presence is a concept that is poorly defined in the literature. It has often been used synonymously with other terms such as caring (Finfgeld-Connett, 2006; 2008a; 2008b), the art of nursing (Finfgeld-Connett, 2008b), empathy, therapeutic use of self, support, and nurturance (Finfgeld-Connett, 2006). Presence has been described as “an interpersonal process that is characterized by sensitivity, holism, intimacy, vulnerability and adaptation to unique circumstances. It consists of a process in which patients demonstrate a need for and openness to presence. In turn, nurses must be willing to enact presence and practice within an environment that is conducive to it” (Finfgeld-Connett, 2006, p. 708). Given the similarities between presence, caring, the art of nursing, and other similar concepts, presence can be differentiated in that it espouses the willingness to be with a person in an authentic way despite the system-level constraints that can prevent nurses from doing so. In today's task-oriented health care system that focuses on efficiency, numbers, and standardized and measurable practice methods, many nurses are driven away from the bedside to attend to paperwork, administrative duties, and other related tasks. This results in nurses feeling disconnected from their practice and unsupported in their attempts to be present with their patients (Melnechenko, 2003). Being truly present with one's patient means that the nurse is open to engaging with him/her in a way that allows expression of individual meanings of a given health experience. Being present does not take more time, it is simply a more focused way of interacting in which the nurse lets go of his or her own concerns and calls for the sharing of oneself through full attention to the other” (Melnechenko, 2003, p. 19). Being present, like the art of nursing and caring, also results in improved mental well-being for the patient and nurse and an improved physical well-being for the patient (Finfgeld-Connett, 2008a).

Cultural competence: "Cultural competence refers to an ability to interact effectively with people of different cultures. Cultural competence comprises four components: (a) Awareness of one's own cultural worldview, (b) Attitude towards cultural differences, (c) Knowledge of different cultural practices and worldviews, and (d) cross-cultural skills. Developing cultural competence results in an ability to understand, communicate with, and effectively interact with

people across cultures" (Martin & Vaughn, 2007, Retrieved September 4th, 2009 from http://en.wikipedia.org/wiki/Cultural_competence#cite_note-0).

Dignity: "Dignity is a term used in moral, ethical, and political discussions to signify that a being has an innate right to respect and ethical treatment" (McDougal, Lasswell, & Chen, 1980, Retrieved Sept 3, 2009 from <http://en.wikipedia.org/wiki/Dignity>).

Evidence-based practice: "Evidence-based decision-making is a continuous interactive process involving the explicit, conscientious and judicious consideration of the best available evidence to provide care. Although rating systems have been developed to rank order this evidence, it is imperative to acknowledge that the use of the higher levels of evidence does not eliminate the need for professional clinical judgment nor for the consideration of client preferences. Evidence is information acquired through scientific evaluation of practice. Types of evidence include experimental studies such as randomized controlled trials and meta-analysis, non-experimental research studies that include quasiexperimental and observational studies, expert opinion in the form of consensus documents and commission reports and historical or experiential information. Evidence-based nursing refers to the incorporation of evidence from research, clinical expertise, client preferences and other available resources to make decisions about clients. Decision-making in nursing practice is influenced by evidence and also by individual values, client choice, theories, clinical judgment, ethics, legislation and practice environments" (CNA, November, 2002, p. 1).

Hospice Palliative Care: Hospice palliative care is aimed at relieving suffering, improving quality of life, and providing comfort and dignity for persons who are living with an advanced life threatening illness or are bereaved through vigilant control of symptoms and restoration of functional capacity while remaining sensitive to personal, cultural and religious values, beliefs and practices. It is the comprehensive management of the physical, psychological, social, spiritual and existential needs of patients and families (Ferrell & Coyle, 2006; Ferris, et al, 2002; Smith, 2000). "Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family" (Robert Wood Johnson Foundation, 1997, cited in Smith, 2000, p.3; also supported by Ferrell & Coyle, 2006).

Holistic: Holistic/wholistic pertains to a philosophical approach that "views the individual and his or her environment in its entirety" (Gorman & Sultan, 2008, p. 7). It is grounded in "a whole person perspective that views people as having integrated physical, emotional, social, and spiritual dimensions. Alterations in one dimension always affect the other dimensions" (Meraviglia, Gaskamp, & Sutter, 2009, p. 502). Hospice palliative care takes a holistic approach that recognizes the need to care for the whole person; body, mind, and spirit (McIntosh & Zerwekh, 2006). To this end, "hospice palliative care strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears" (Ferris, et. al, 2002, p. 113).

The concept of holism enables one to consider human beings as dynamic, having interrelated dimensions affected by the changes and adaptations experienced with progressive illness and dying. "These dimensions involve the physical experience of end-of-life stage disease, emotional experience of one's relationships and how one defines spiritual existence...Life perspectives,

goals and needs change as the disease progresses and the physical dimensions decline...It is a time of reflection on a broader sense of meaning, purpose and relationships based on each individual's values. The palliative approach grew from this understanding of full personhood and is designated to offer expert end-of-life care to patients and families" (Ferrell & Coyle, 2006, p.14). It addresses all of these dimensions (Wasserman, 2007; Maher & Hemming, 2005) through an interdisciplinary team approach (Rolling Ferrell & Coyle, 2001; Mauk & Schmidt, 2004). It "requires the fostering of hope, choice and autonomy which help people to adapt to illness more effectively" (Rideout & Montemuro, 1986, cited in Lugton & Kindlen, 1999, p. 66). "Holistic nursing involves sharing information with the patients and relatives who are then involved in setting goals and making decisions" (Lugton & Kindlen, 1999, p. 67).

Interprofessional: "An interprofessional process of communication and decision making that enables the separate and shared knowledge and skills of health care providers to synergistically influence the client/patient care provided" (Way & Jones, 2000, as cited in Health Canada, 2006, p. 2). [It] "is designed to promote the active participation of several health care disciplines and professions. It enhances patient-, family-, and community-centred goals and values, provides mechanisms for continuous communication among health care providers, optimizes staff participation in clinical decision making (within and across disciplines), and fosters respect for the contributions of all providers" (Health Canada, 2006, Retrieved September 4, 2009 from <http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/interprof/index-eng.php>).

"Each patient and family is supported by an interdisciplinary team consisting of physicians, nurses, social workers, counsellors, chaplains, therapists, home health aides, and volunteers. These disciplines reflect the expertise needed to address the varied dimensions affected through the course of illness, dying, and bereavement" (Ferrell & Coyle, 2006, p. 14). Interprofessional teams must include, listen to and recognize each member and his expertise, have a shared philosophy and values oriented toward the patient/family experience, and develop skills to communicate efficiently (free translation, Société française d'accompagnement et de soins palliatifs, 1999).

Suffering: "A state of distress associated with events that threaten the intactness of a person. It may be accompanied by a perceived lack of options for coping" (Ferris et. al, 2002, p.96). Ferrell & Coyle (2008, p 108) build on the pioneering work on suffering done by Eric Cassell and others and have identified the following tenets about the nature of suffering by patients and families and the goals of nursing in responding to their needs. These tenets may apply to the suffering that nurses witness in patients, families, colleagues, and themselves.

1. Suffering is described as a loss of control, which creates insecurity. Suffering people often feel helpless and trapped, unable to escape their circumstances.
2. In most instances, suffering is associated with loss. The loss may be of a relationship or of some aspect of the self, or loss of some aspect of the physical body. The loss may be evident only in the mind of the sufferer, but it nonetheless leaves a person feeling diminished and with a sense of brokenness.
3. Suffering is an intensely personal experience.
4. Suffering is accompanied by a range of intense emotions including sadness, anguish, fear, abandonment, despair and a myriad of other emotions.

5. Suffering can be deeply linked to a recognition of one's own mortality. When threatened by serious illness, people may fear the end of life. Conversely, for others, living with a serious illness may cause a yearning for death.
6. Suffering often involves the question "Why?" Illness or loss may be seen as untimely and undeserved. Suffering people seek to find meaning for that which is unknowable.
7. Suffering is often associated with separation from the world. Individuals may express intense loneliness and yearn for connection with others while also feeling intense distress about dependency on others.
8. Suffering is often accompanied by spiritual distress. Regardless of religious affiliation, individuals experiencing serious illness may feel a sense of hopelessness. When life is threatened, there may be a self-evaluation of what has been lived and what remains undone. Becoming weak and vulnerable facing mortality may cause one to reevaluate his/her relationship with a higher being.
9. Suffering is not synonymous with pain but is closely associated with it. Physical pain is closely related to psychological, social, and spiritual distress. Pain which persists without meaning becomes suffering.
10. Suffering occurs when the individual feels voiceless. This may occur when the person is mute to give words to their experience or when their "screams" are unheard.

References

- Anwari, J. S. (2008). Pain and ethics. *The Internet Journal of Health*, 7(1), Retrieved September 4, 2009 from <http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijh/vol7n1/ethics.xml>.
- Ars, B., & Montero, E. (2004). *Suffering and dignity in the twilight of life*, Kugler Publications: Hague, Netherlands.
- Austin Hurtig, W., & Stewin, L. (1989). The effect of death education and experience on nursing students' attitude toward death. *Journal of Advanced Nursing*, 15(1), 29-34.
- Beth-El College of Nursing & Health Sciences (2001). *Student Handbook: A Guide to Life at Beth-El College, 2006-2007*, Retrieved September 4, 2009 from http://web.uccs.edu/bethelstudenthandbook/definition_of_curriculum_terms.htm.
- Canadian Association of Schools of Nursing (CASN). (March 16, 2007). *Report on the CASN Palliative Care Symposium*. Ottawa, ON: Author.
- Canadian Hospice Palliative Care Association (CHPCA) Nursing Standards Committee (2002). *Hospice Palliative Care Nursing Standards of Practice*. Ottawa, ON: Author.
- Canadian Hospice Palliative Care Association. (December, 2006). *The Pan-Canadian Gold Standard for Palliative Home Care*. Ottawa, ON: Author.

- Canadian Nurses Association (CNA). (November, 2002). *Position Statement: Evidence-Based Decision-Making and Nursing Practice*. Retrieved September 4, 2009 from http://www.cnanurses.ca/CNA/documents/pdf/publications/PS63_Evidence_based_Decision_making_Nursing_Practice_e.pdf.
- Canadian Nurses Association. (2005). *Primary Health Care: A New Approach to Health Care Reform*. Retrieved August 20, 2009 from http://www.cna-aiic.ca/CNA/documents/pdf/publications/PHC_presentation_Kirby_6602_e.pdf
- Canadian Nurses' Pain Issues Working Group. (August, 2005). *Pain Management: A Patient Safety, Quality Work Life, and Social Justice Issue for Nursing?*
- Carstairs, S. (2000). *Quality End-of-Life Care: The Right of Every Canadian: Subcommittee to Update of Life and Death of the Standing Senate Committee on Social Affairs, Science and Technology*. Ottawa, ON: The Senate.
- Carstairs, S. (2005). *Still Not There, Quality End-of-Life Care: A Progress Report*. Ottawa, ON: The Senate.
- Caty, S., & Tamlyn, D. (1984). Positive effects of education on nursing students' attitudes toward death and dying. *Nursing*, 16(4), 41-53.
- Davies, B. & Oberle, K. (1990). Dimensions of the supportive role of the nurse in palliative care. *Oncology Nursing Forum*, 17(1), 87-94.
- Doane, G. & Varcoe, C. (2005). *Family as Relational Inquiry: Developing Health Promoting Practice*. New York, NY: Lippincott, Williams, and Wilkins.
- Downe-Wamboldt, B., & Tamlyn, D. (1997). An international survey of death education trends in faculties of nursing and medicine. *Death Studies*, 21(2), 177-188.
- Ferrell, B. (2005). Ethical perspectives on pain and suffering. *Pain Management Nursing*, 6(3), 83-90.
- Ferrell, B. & Coyle, N. (2008). *The Nature of Suffering and the Goals of Nursing*. Oxford University press: New York.
- Ferrell, B. R., & Coyle, N. (Eds.). (2006). *Textbook of Palliative Nursing (2nd Ed.)*. New York: Oxford Press.
- Ferrell, B.R., Virani, R., Grant, M., Rhome, A., Malloy, P., Bednash, G., Grimm, M. (2005). Evaluation of the end-of-life nursing education consortium undergraduate faculty training program. *Journal of Palliative Medicine*, 8, 107-114.

- Ferris, F.D., Balfour, H.M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., West, P. (2002). A model to guide patient and family care: Based on nationally accepted principles and norms of practice. *Journal of Pain and Symptom Management*, 24(2), 106-123.
- Finfgeld-Connett, D. (2006). Metasynthesis of presence in nursing. *Journal of Advanced Nursing*, 55(6), 708-714.
- Finfgeld-Connett, D. (2008a). Qualitative comparison and synthesis of nursing presence and caring. *International Journal of Nursing Terminologies and Classifications*, 19(3), 111-119.
- Finfgeld-Connett, D. (2008b). Qualitative convergence of three nursing concepts: Art of nursing, presence, and caring. *Journal of Advanced Nursing*, 63(5), 527-534.
- Gardner, D. 1985. Presence. In G. Bulechek & J. McCloskey (Eds.), *Nursing Interventions: Treatments for nursing diagnosis* (pp. 316-324). Philadelphia: Saunders.
- Gorman, L., & Sultan, D. (2008). *Psychosocial Nursing for General Patient Care*. Philadelphia, PA: F.A. Davis.
- Green, L.W. (2001). From research to best practices in other settings and populations. *American Journal of Human Behavior*, 25, 165-178.
- Halliday, L. E., & Boughton, M. A. (2008). The moderating effect of death experience on death anxiety. *Journal of Hospice and Palliative Nursing*, 10(2), 76-82.
- Health Canada (2006). *Interprofessional Education for Collaborative Patient-Centred Practice: Research Workshop Final Summary Notes*, Retrieved September 4, 2009 from http://www.cihc.ca/files/IECPCP_Research_Workshop_Final_Summary_Notes_May06.pdf
- Hurtig, W. A., & Stewin, L. (1989). The effect of death education and experience on nursing students' attitude towards death. *Journal of Advanced Nursing*, 15(1), 29-34.
- Kahn, D. L., & Steeves, R. H. (1986). The experience of suffering: Conceptual clarification and theoretical definition. *Journal of Advanced Nursing*, 11, 623-631.
- Liehr, P. (1989). The core of true presence: A loving center. *Nursing Science Quarterly*, 2(1), 7-8.
- Lugton, J., & Kindlen, M. (1999). *Palliative Care: The Nursing Role*. Edinburgh, England: Churchill Livingstone.
- Maher, D., & Hemming, L. (2005). Understanding patient and family: Holistic assessment in palliative care. *British Journal of Community Nursing*, 10(7), 318-322.

- Mallory, J. L. (2003). The impact of a palliative care educational component on attitudes toward care of the dying in undergraduate nursing students. *Journal of Professional Nursing*, 19(5), 305-312.
- Martin, M., & Vaughn, B. (2007). Strategic Diversity & Inclusion Management magazine, pp. 31-36. DTUI Publications Division: San Francisco, CA. Retrieved September 4th, 2009 from http://en.wikipedia.org/wiki/Cultural_competence#cite_note-0
- Mauk, K. L., & Schmidt, N. A. (2004). *Spiritual Care in Nursing Practice*. Philadelphia, PA: Lippincott, Williams, & Wilkins.
- McDougal, M. S., Lasswell, H. D., & Chen, L., *Human Rights and World Public Order: The Basic Policies of an International Law of Human Dignity* (New Haven: Yale UP, 1980), note, at 376. Retrieved Sept 3, 2009 from <http://en.wikipedia.org/wiki/Dignity>
- McIntosh & Zerwekh (2006). Hospice and palliative care. In J. F. A Zerwekh (Ed.), *Nursing Care at the End of Life: Palliative Care for Patients and Families*. Philadelphia, PA: Davis.
- Melnechenko, K.L. (April-June, 2003). To make a difference: Nursing presence. *Nursing Forum*, 38(2), 18-24.
- Meraviglia, M., Gaskamp, C., & Sutter, R. (2009). Spiritual distress in people with cancer. In C. Chernecky & K. Murphy-Ende (Eds.), *Acute Care Oncology Nursing*. St. Louis, MO: Saunders Elsevier.
- Mok, E., Lee, W. M., & Wong, F. K. (2002). The issue of death and dying: Employing problem based learning in nursing education. *Nurse Education Today*, 22(4), 319-329.
- O’Gorman, S. M. (1998). Death and dying in contemporary society: An evaluation of current attitudes and the rituals associated with death and dying and their relevance to recent understandings of health and healing. *Journal of Advanced Nursing*, 27, 1127-1135.
- Parse, R.R. (1991). Mysteries of health and healing: Two perspectives. *Nursing Science Quarterly*, 4, 93.
- Parse, R.R. (1992). Human becoming: Parse’s theory of nursing. *Nursing Science Quarterly*, 5, 35-42.
- Parse, R.R. (1994). Quality of life: Sciencing and living the art of human becoming. *Nursing Science Quarterly*, 7(1), 16-21.
- Peter, E., Lunardi, V.L., & Macfarlane, A. (2004). Nursing resistance as ethical action: literature review. *Journal of Advanced Nursing*. 46, 403-416.

- Peter, E., & Watt-Watson, J. (2002). Unrelieved pain: An ethical and epistemological analysis of distrust in patients. *Canadian Journal of Nursing Research, 34*, 65-80.
- Pettigrew, J. (1990). International nursing care: The ministry of presence. *Critical Care Nursing Clinics of North America, 2*, 503-508.
- Pierce, S. F., Dalton, J. A., & Duffey, M. (2001). The nurse's ethical obligation to relieve pain: Actualizing the moral mandate. *Journal of Nursing Law, 7*(4), 19-26, 28.
- Rees, J., King, L., & Schmitz, K. (2009). Nurses' perceptions of ethical issues in the care of older people. *Nursing Ethics, 16*, 436-452.
- Roach, M.S. (1997). Reflections on the theme. In M. Roach (Ed.), *Caring from the heart: The convergence of caring and spirituality*(pp. 7-20). New York: Paulist Press.
- Rogers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing, 25*, 1048-1053.
- Sabo, B. (2006). Compassion fatigue and nursing work: Can we accurately capture the consequences of caring work? *International Journal of Nursing Practice, 12*, 136-142.
- Safran, D., Miller, W., & Beckman, H. (2006). Organizational dimensions of relationship-centered care theory, evidence, and practice. *Journal of General Internal Medicine, 21*, S9-S15.
- Smith, S. A. (2000). *Hospice Concepts: A Guide to Palliative Care in Terminal Illness*. Champaign, Illinois: Research Press.
- Société française d'accompagnement et de soins palliatifs. (1999). *L'infirmier(e) et les soins palliatifs, « Prendre soin » : éthique et pratiques*. Paris : Masson.
- Van Hooft, S. (1998). The meanings of suffering. *Hasting Center Report, 00930334, September 1, 1998, 28*(5). Retrieved July 29, 2009 from Philosopher's Index.
- Wasserman, L. S. (2007). Respectful death: A model for end-of-life care. *Clinical Journal of Oncology Nursing, 12*(4), 621-626.
- Watson, J. (1985). *Nursing: Human science and human care*. Norwalk, CT: Appleton Century.
- Wilson, D., Northcott, H., Truman, C., Smith, S., Anderson, M., Fainsinger, R. & Stingl, M. (2001). Location of death in Canada: A comparison of 20th century hospital and non hospital locations of death and corresponding population trends. *Evaluation and the Health Professions, 24*(4), 385-403.
- World Health Organization (2009). *WHO definition of palliative care*, Retrieved

September, 2009 from <http://www.who.int/cancer/palliative/definition/en/>