The Experiences of Cancer Nurses’ Existential Care in Response to the Threat of Patients’ Mortality within the Culture of Cure

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ABSTRACT

Patients are living longer with many types of cancer; however, often they face sudden possibilities of dying, not only due to their advancing illness but due to complications of their treatment. Consequently, they can express substantial existential distress. Nurses’ close proximity to patients puts them in an ideal place to assess and engage with patients’ existential distress; yet this kind of research has been scarce. The purpose of this doctoral thesis was to explore nurses’ experiences of being with patients facing the threat of mortality. Yalom describes this threat as the fear of death, isolation, anxiety and responsibility about freedom, and meaninglessness. The study took place in a cancer setting where care is highly technological and goals of cure dominate, specifically, two bone marrow transplant units of one institution in Canada. Benner’s methodology of interpretive phenomenology guided data collection and analysis of focused observations and interviews with 19 registered nurses. The experience of fighting cancer while preparing for the possibility of letting go was the main theme. Letting go did not reflect nurses’ intents to abandon life but to release patients (if only briefly) from perceived norms of the curative culture. More specifically, the main theme was characterized by: 1) working within the culture of cure and the possibilities of patients dying, 2) concern about “bursting the bubble of hope,” 3) whether to and how to respond to patients’ distress and dying, and 4) coping with patient involvement. In the context of responsive relationships (patients and
their families, and healthcare colleagues), nurses reported engaging in communication about the threat of patients’ mortality, and responding with letting be and supporting families to let go, the management of technology and prevention of technological intrusions, and striving for patients to have “easier” deaths. Results indicate a potential to enhance nurses’ supportive care constituted by their perceived responsibility to engage and respond to patients’ existential distress. Moreover, this study suggests that more attention is warranted not only to policy, education, and research that focuses on patients’ existential well-being, but to the well-being of nurses working within tensions of curing and comforting.
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AGENCY
The sense of self-efficacy, engagement, and sense of responsibility in stories nurses tell. It stems from a source of reflection and conflict. It is not just a matter of assertiveness, social negotiation, or “choosing” to take responsibility, but being in a position to “see” the certain choices that are possible and that these choices typically have certain consequences (Benner, et al., 1996, p. 49).

BACKGROUND MEANING
Shared public understanding of what matters or counts as real for the person, allowing for perceptions of the factual world. These meanings originate from the culture, subculture, family, and personal life experiences of the person (Benner & Wrubel, 1989, p. 407).

COMMON MEANING
Meanings taken-for-granted in local language and culture. These meanings create what is noticed and what are possible issues, agreements, and disagreements between people (Benner, 1994, p. 105).

CONCERN
The way a person is oriented meaningfully to their situations. It dictates what will show up as mattering to him/her. They are based on underlying ethical and existential beliefs (Benner, 1994, p. 105).

EMBODIED
“The ways meanings, expectations, styles, and habits are expressed and experienced in the body” (Benner, 1989, p. 409) in relationships with others based on a context of historical self-understanding and his/her current life situation. Embodied know-how is response-based practice using skilled knowledge for identification, timing, and performance required in the context of quickly grasping needs of a particular situation (Benner & Wrubel, 1989, p. 173).

EMOTIONAL ATTUNEMENT
The appropriate level of involvement and tone with patients/families. Concern and emotional connection to the patient/ family allow the nurse to perceive both patient distress and enable the nurse to respond in attuned ways their situation (Benner, et al., 1996, p. 118).

EXISTENTIAL
The meaningful ways an individual’s life is connected to others and/or is guided towards a future, particularly when conditions of existence are challenged (Yalom, 1980, p. 8).

EXISTENTIAL CARE
Health care provider’s work exploring the personal meanings and concerns of how the self interacts with or is connected to others, and/or is guided towards a future by the presence and influence of an omnipresent deity/god (Whitehead, 2003, p. 680).

FREEDOM
The perceived responsibility and will that is available in a network of social relationships, meanings, concerns, and equipment (Yalom, 1980, p. 220). Situated freedom occurs when people have certain choices and actions against the background of their situation. Depending on a
person’s situation, certain choices are more relevant and appealing than others (Benner & Wrubel, 1989, p. 412).

**SKILL OF INVOLVEMENT**
Knowledge that guides emotional involvement with others to sensibly facilitate groups and individuals in mutual goals of concern. *Skilled involvement* consists of practical know-how and sensitive ethical judgment acquired by experiences of learning to be actively involved in situations that allow intuitively grasping "correct" perceptions of the whole and not its precepts (Bennner, et al., 1996, p. 91).

**SITUATION**
An understanding of how the person is situated, both historically and currently. Questions related to the situation are whether the situation is understood as a smooth social functioning one or as a breakdown situation of novelty, error, confusion, or conflict (Benner & Wrubel, 1989, p. 412).

**SITUATED MEANING**
Meanings based on patients’ particular concerns, issues, and resources given the place and moment in time (Benner & Wrubel, 1989, p. 15).

**SITUATED POSSIBILITY**
The actions that show up as possibilities or choices within the context of how people are engaged through concern with their current situation (Benner & Wrubel, 1989, p. 412).

**TEMPORALITY**
The experience of lived time (more than linear succession of time). It is the way one projects oneself into the future and understands oneself from the past. It includes the sense of timelessness or time being radically altered (Benner & Wrubel, 1989, p. 412).

**THREAT OF MORTALITY**
A fear of death, mortal terror, fear of finitude related to a fear of the future and its fragility. According to Yalom (1980), the four cornerstones threatening existence are: 1) fear of death; 2) isolation; 3) freedom to anxiety pervasive of creating and controlling our destiny; and 4) meaninglessness (p. 213).
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PROLOGUE

Rigour in research involves the aid of a researcher's active presence to inform the reader of the position in which to apprehend the nature of the inquiry (Eakin & Mykhalovskiy, 2003). According to Eakin and Mykhalvskiy (2003), the researcher's subjectivity is not seen as a problem of bias to be eliminated or reduced but "as something to be used actively and creatively throughout the research process" ..."as a resource" (p.191). Thus, I start with an excerpt from my research journal reflecting on a personal story, which is at the heart of my inquiry. It invites the reader to apprehend and scrutinize both the conceptualization of the research process and the substantive analysis.

My sister-in-law, Loletta, was a 35 years old mother, wife, accountant, daughter, sister, and friend. One morning at work, she suffered a sudden heart attack and descended into a coma. Family and healthcare professionals in the intensive care unit (ICU) attempted to focus on conversations near the end of her life about the need to give meaning to her death. Prior to any awareness of dying, Loletta expressed a wish to donate her organs if anything should happen to her and if she should die. Yet despite this wish to give meaning to her death, we all suffered tremendous grief in her dying, especially her husband and her parents. In retrospect, I recognize we suffered from a sense of a lack of meaning in why she was dying. We were completely unprepared to comprehend her dying, let alone engage in conversations about a notion of her death. The ICU nurses and physicians encouraged us to donate Loletta's organs. When family conflict and our grief reached a crisis, most of the medical and nursing staff avoided talking with us. Instead, they suggested psychiatric counseling. As a mental health nurse myself, I resisted medicalizing what I perceived was a process of normal distress and grieving, yet sympathized with clinicians' reluctance to engage in our suffering.

When the decision was made against organ donation, medical staff insisted that my brother-in-law consent to allowing his wife to die, so that a bed could be made available for the
next patient waiting in emergency. The attitude of the clinicians triggered angry protests from Loletta's husband and her immediate family. They challenged the clinicians to value Loletta as a person who remained connected with others, and not relegate her to merely an object as a means to an end. In that moment, I was jarred into an awareness of my own professional identity as a nurse, having similarly approached patients in this manner. I felt appalled and ashamed by their behaviour...and by my past behaviour. For me, this story unfolded from the point of view of a family member and doing so, it motivated and engaged me to start conversations that reflect on the role and scope of nurses to attend to the threat of patients' mortality.

When Loletta was in a coma, it was incumbent upon us to engage in conversations to give meaning to her dying. When I say I needed to give meaning to her dying, I mean meaning that is not for her or about her but for and about us in relation to our sensibilities of place and sense of belonging in this world. I could not accept Loletta's death until I could accept the possibility of her dying and death being mine. I began to wonder whether when we are with someone who dies, perhaps we suffer not only from the loss of our relationship with them, but in our own threat of mortality.

Since then, my concern is in comprehending the fragility of life motivated by gaps I have perceived between the acknowledgement and amelioration of psychosocial distress that includes the threat of morality wherein our future is uncertain.
CHAPTER I: INTRODUCTION,
RESEARCH PURPOSE AND QUESTIONS,
SIGNIFICANCE OF THE STUDY, AND PROBLEM STATEMENT
Introduction

Cancer is the leading cause of premature death in older Canadians (Canadian Cancer Society's Steering Committee, 2010). Current incident rates predict cancer will develop in 48.3% of Canadian women and 51.7% of Canadian men during their lifetimes. In effect, an average of 173,800 Canadians will be diagnosed with cancer and 76,200 people will die of cancer in the year 2010. As patients' testimonies demonstrate, cancer is a particular threat where one's future is endangered (Skott, 2002).

The incidence of cancer is increasing primarily due to an aging and a growing population; however, mortality rates for most cancers have declined (Canadian Cancer Society’s Steering Committee, 2010). In men, mortality rates from 1996 to 2005 declined by at least 18% altogether for cancers of the lung, oral, prostate, and larynx. In women, mortality rates since 1981 have declined about 20% for all types of cancers except lung cancers, and in all age groups except for those over 70 years of age (when the mortality rate is slightly higher). As a result, more often cancer is perceived as a chronic illness (Devins et al., 2006) and afflicting older people, who will have to tolerate a growing awareness to the threat of mortality and possible imminence of their deaths.

The disclosure of a life-threatening diagnosis or even the risk of its genetic inheritance (Esplen et al., 2003) heightens a person's awareness about his/her mortality (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). A diagnosis of cancer is experienced as suffering and as a trigger for examining meaning in one’s life (Lethborg, Cox, & Kissane, 2007), both consciously and unconsciously (Yalom, 1980). According to Mickley et al., (1992), the term existential is the "humanistic values, beliefs, attitudes and principles that guide and direct an individual's life" (Whitehead, 2003, p. 680). Existential ideas support a personal search for meaning and purpose in life, which may or may not be related to religion. The threat of mortality triggers a search for guidance and direction based on the assumption that “all human beings possess an inherent
desire and ability to transcend hardship and suffering through their own personal capacity”

Cancer patients experience a kind of suffering as the threat of mortality. The threat of mortality is a "fear of death, mortal terror, fear of finitude" (Yalom, 1980, p.42) related to a fear of the future and its fragility (Yalom, 1980). Patients’ reactions range from shock and disbelief, to occasionally, more considerable distress two to three months after a cancer diagnosis (Kruijver, Kerkstra, Bensing & van de Wiel, 2000). Distress from the threat of mortality may fluctuate hourly or daily as cancer patients experience consciously and unconsciously the will to live (Chochinov, et al., 1999). Individuals with cancer have demonstrated levels of up to 42% to 50% of them experiencing psychiatric disorders, such as depression, anxiety, and potential neurocognitive changes, including delirium (Sivesind & Baile, 2001), particularly in advanced or terminal stages of their illness (Vachon, 2004; Zabalegui, 1999). Existential distress in cancer patients is found to be strongly correlated with end-of-life despair, even after controlling for the effect of depressive symptoms, physical symptoms, and social support (McClain, Rosenfeld, Breitbart, 2003). Though existential concerns are pervasive in the cancer population, the acknowledgement by patients of existential issues does not necessarily lead to significant distress and may even enhance a deepened meaning of life (Arman & Rehnsfeldt, 2003; Griffiths, Norton, Wagstaff, & Brunas-Wagstaff, 2002).

To prevent unnecessary distress, frontline health care providers, and in particular nurses, need to assess and engage in patients’ feelings of existential distress to prevent it from being associated with helplessness and hopelessness (Chochinov, et al., 1995, 1999). While therapeutic relationships may not prolong survival, the prevention and amelioration of suffering that can lead to depression is possible (Kissane et al., 2007). Furthermore, attending to these concerns can facilitate a freedom that engages individuals in an authentic experience and in the

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capacity to make choices, all of which can assist in dealing with issues of coping with prognoses and decisions near the end of life (Lee, Cohen, Edgar, Laizner, & Gagnon, 2006).

The Trajectory of Cancer and Existential Care

Traditionally, existential distress was a focus of therapy when patients were recognized to be approaching the end of their lives (Aranda & Milne, 2002). The definition of palliative care by the World Health Organization (WHO) in 1986 established an awareness that health care providers needed to sequentially respond to patients’ existential distress when they were no longer responsive to “curative” anti-cancer treatment (Ahmedzai, et al., 2004). Today, the greatest limitation of this sequential model is in how a cancer diagnosis is experienced by patients as a chronic life-threatening disease, particularly when the distinction between acute and palliative care is narrower (Ahmedzai, et al., 2004) and patients are more likely to have rapid multi-organ failure towards the end of their lives (World Health Organization Europe, 2004). As such, there is a need to attend to the threat of patients’ mortality in earlier stages of a cancer diagnosis and during critical moments in which patients may be transitioning from acute to palliative care. This kind of care may follow “palliative intents” as opposed to being palliative care (Jefford, Milne, Aranda, & Schofield, 2007). Existentially-oriented care that supports intents of palliation when patients consider the possibility of dying or when the potential for death becomes imminent may alleviate patients’ emotional distress, and assist to prevent it from continuing or escalating. As such, care that contains palliative intents may be particularly helpful when patients face risks of complications from curative treatment.

Existing care explores personal meanings and concerns of how the self interacts with or is connected to others, and/or is guided towards a future by the presence and influence of an omnipresent deity/god (Whitehead, 2003). Notably, discourse has evolved beyond matters of an externalized influence to a fundamental internalized search for meaning (Whitehead, 2003).
Whitehead's (2003) literature review describes existential care as more than religious-based responses. Indeed, the beneficial aspects of religion may primarily be those that relate to spiritual well-being rather than religious practices per se, as reported in a sample of terminally ill patients with cancer and AIDS (n= 162) (Nelson, Rosenfeld, Breitbart and Galietta, 2002).

*Cancer Nurses and their Work in Supportive Care*

According to the Canadian Nurses Association (2009), about four percent or 3,129 registered nurses work in the area of oncology in Canada. The average age of these nurses is 41.3 years, 90.54% are female, and 77.47% work in hospitals (CNA, 2009). Cancer nurses are positioned in close physical and moral proximity to patients, enabling nurses opportunities to talk to patients about their experiences related to the threat of mortality and dying. They are a central member of cancer treatment and care teams, and are key participants impacting on health policy (Corner, 2001).

*Supportive care* has been defined as:

the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, informational, emotional, psychological, social, and spiritual needs during the pre-diagnostic, diagnostic, treatment, and follow-up phases, encompassing issues of survivorship, palliation and bereavement (Fitch, 2000).

While all cancer patients require supportive care on an ongoing basis for emotional support, good communication, and symptom management, an average of 35% to 40% of patients require additional support. This includes specialized care for psychosocial distress. Additionally, another 10% to 15% require intensive and ongoing complex interventions (Fitch, Porter, & Page, 2008).

Oncology nursing standards (CANO, 2008) used by nurses to guide and regulate practice include advanced assessment and communication skills to facilitate engagement through patients’ illness experiences. Nursing standards following supportive care report clear gains at symptom management for cancer patients; however, nurses still appear to be challenged...
attending to emotional distress, including existential issues (Fitch & Steele, 2008). Reasons for this include individual, professional, interdisciplinary, environmental or organizational reasons. Nurses may respond by ignoring or avoiding communication about prognosis, and favour medical-technical or corporate agendas of treatment and information (de Carvalho, Muller, de Carvalho, & de Souza Melo, 2005; Georges, Grypdonck, & de Casterle, 2002; Willard & Luker, 2005). Many nurses report that they have little time or lack the "know how" to engage and/or support patients in discussions about advance directives (Jezewski, Meeker, & Schrader, 2003). When patients report concerns or fears around having a life-threatening illness, nurses express regret and guilt that they have left patients and their families with unresolved feelings and issues (Steinhauser et al., 2001).

Care that demonstrates a concern for the threat of mortality is increasingly recognized as part of quality of life and needs to occur in all phases of the cancer continuum as part of basic clinical oncology practice (Ahmedzai et al., 2004). Along with communication challenges, studies are beginning to identify the role of organizational culture and its impact on oncology care (Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Dunne & Sullivan, 2000; Johnston & Abraham, 2000; Pincombe, Brown, & McCutcheon, 2003; Ronaldson & Devery, 2001). Given these challenges, it is unclear how nurses enact competencies described in nursing standards in efforts to reduce patients’ existential distress.

The Threat of Mortality in Hospitals: Inpatient Bone Marrow Transplant Units

Research about assessing and intervening with patients’ existential distress and suffering in acute care settings is very scarce (LeMay & Wilson, 2008). Attending to existential issues is particularly important when they arise not only from patients' experiences of illness, but also because they are triggered intrinsically by everyday hospital routines (Whitehead, 2003). Patients in “curative” cultures tend to report a greater amount of physical symptoms (e.g. fatigue,
nausea and vomiting, dyspnea, sleep disturbance, appetite loss, constipation, diarrhea) compared with those being cared for in “care-oriented” cultures, such as in hospice wards or nursing homes, with the exception of reported amounts of pain (Sahlberg-Blom, Ternestedt, & Johansson, 2001). Additionally, quality of life measurements of patients in “care-oriented” cultures are also somewhat higher than those in “cure-oriented” cultures (Sahlberg-Blom et al., 2001).

One acute care setting where potential challenges to existential care occur is the hematology oncology bone marrow transplant unit. This setting represents a place where a cure-oriented culture dominates, as technology aims to prolong patients’ lives and makes it possible for patients to experience positive signs of recovery even close to death (McGrath & Holewa, 2007). An estimated 18,720 people in North America had autologous or allogeneic bone marrow transplantation for blood cancers in 2005 (Center for International Blood and Marrow Transplant Research, 2007). Fifty-six percent (56%) of patients with multiple myeloma and lymphoma commonly received autologous bone marrow transplantations; whereas the most common indication for allogeneic bone marrow transplantation was acute leukemia (Centre for International Blood and Marrow Transplant Research, 2007). To date, many forms of leukemia are considered fatal and bone marrow transplantation is acknowledged to be the only possible cure (Kelly, Ross, Gray, & Smith, 2000).

Bone marrow transplantation has contributed to longer survival for patients with hematological malignancies. For instance, the median survival for patients with multiple myeloma after conventional treatments is 3 to 4 years; whereas high dose treatment followed by autologous stem cell transplantation can extend median survival to 5 to 7 years (Raab, Podar, Breitkreutz, Richardson, & Anderson, 2009). However, the invasive nature of the treatments puts patients in a highly vulnerable and disempowered position when they face transplant related complications or relapse of their primary disease (Mcgrath & Holewa, 2007).
Particularly, in acute cancer services, such as an inpatient hematology service, where patients face high risks of morbidity and mortality, cancer nurses need to be even more cognizant of patients' feelings of existential distress. Patients express living in a "provisional" existence, exacerbated by psychological deprivation from isolation procedures, while they deal with their diagnoses, prognoses, and the decision to have aggressive cancer treatment, such as bone marrow transplantation (Steeves, 1992). Patients state that they move "in and out" of crises brought about by an awareness of the threat of mortality and potential dying (Jones & Mitchell, 2003).

Bone marrow transplantation involves a long hospitalization (i.e., on average 30 days) with the use of radiation and chemotherapy to destroy the diseased bone marrow and, in doing so, the entire immune system. Toxic effects of the aggressive treatment are severe from the point of physical, psychological, and social consequences. Patients live in a protective environment where they experience isolation for varying periods of time (Kelly et al., 2000). During these times, they experience sloughing and reddening of the skin, alopecia, nausea and vomiting, diarrhea, and severe oral pain that may prevent patients from eating and talking for days at a time (Steeves, 1992). They are often far from home and do not have access to their usual social supports during a long hospitalization. As a result of physical and emotional influences, many individuals undergoing bone marrow transplantation face the greatest threat to their mortality, and report feeling isolated and alone with severe psychological effects (Jones & Mitchell, 2003).

In a study in a medical center in the USA, 43% of 236 adult hematological stem cell transplant survivors continued to suffer a sense of existential isolation even an average of 3.4 years after the transplant procedure (Rusiewicz, et al., 2008).

Patients undergoing bone marrow transplantation often express emotional needs to nurses (Carvalho, Goncalves, Bontempo, & Soler, 2000). The literature suggests that nurses in bone marrow transplant units significantly contribute to the maintenance of patients’ hope (Kelly et al., 2000). Nurses have an opportunity to address fears related to the unknown, including the
potential of cancer recurrence. By coaching and counseling patients through their experiences, nurses are encouraged to provide opportunities to discuss fears and losses, to connect with others who have had bone marrow transplantation, and facilitate ways families can be involved (Cohen & Ley, 2000).

Nurses’ supportive care in inpatient bone marrow transplant services is suggested to be rewarding but also to create a risk of nurses experiencing anxiety arising from their work with human suffering (Kelly, et al., 2000). The emotional labor can be taxing due to the intense relationships that nurses may have with patients, and from the repeated sense of loss, and sometimes futility from the common occurrence of death (Kelly, et al., 2000). A study in the United States (Molassiotis & Haberman, 1996) of bone marrow transplant nurses (n= 49) reported that they experienced high personal growth and personal accomplishment (60%). However, 52.5% of these nurses also reported moderate emotional exhaustion and 22.5% reported a low sense of accomplishment from their job. In this sample, 9 to 10% reported “burnout syndrome” described as a combination of high emotional exhaustion, high depersonalization, and low personal accomplishment (Molassiotis & Haberman, 1996).

Rarely have nurses’ experiences in assisting cancer patients to deal with the life-threatening nature of their illness and treatment been addressed in the empirical literature. The context of bone marrow transplant units provides a particularly relevant context where challenges may be heightened due to the dominant culture of cure and the needs for existential care in this patient population (Kelly et al., 2000). This study will provide further understanding addressing this gap and clarify how cancer treatment, including bone marrow transplantation influences nurses’ existential care.
Research Purpose and Questions

The purpose of this study was to explore nurses’ experiences of being with patients with cancer facing the threat of mortality in bone marrow transplant settings. The specific research questions were:

1. How do nurses experience the threat of patients’ mortality?
2. How do nurses engage with the threat of patients’ mortality?
3. How does the context of the inpatient bone marrow transplant units situate nurses’ work within concerns of the threat of patients’ mortality?
4. How do nurses cope with caring for patients who face the threat of mortality?

Significance of the Study

Benner (2000) suggests that a nurse's involvement in the situation is crucial to the quality of their nurse-patient relationship. Only within the nurse's ability to know herself/himself can she/he begin to know his/her patient. Nurses' perspectives need to be incorporated into health care knowledge of relationships with patients/families. In turn, this knowledge will improve education and training programs to assist nurses to understand the nature and meanings that support the purposes of their care.

While the specific context of this study occurred in bone marrow transplant units, findings may be transferable to other settings where patients' experience life-threatening or serious chronic illnesses. One such setting may be intensive care units, where clinicians are challenged to make sense of their work when complications of treatment occur or when continuing treatment begins to feel futile (Hodde, et al., 2004). Additionally, another similar setting may be cardiac units, where patients want support dealing with vulnerabilities and achieving normalization and resolution of uncertainty (Davidson, et al., 2007).
Problem Statement

Supportive care for patients who experience existential distress and suffering is within the scope and standards of cancer nursing practice; however, little is known about the ways nurses engage in this kind of care. This research poses questions about how nurses experience and engage in existential care with patients at risk of a threat of mortality on inpatient bone marrow transplant units. This knowledge can inform future nursing practice, education, policy, and research that benefits not only nurses, but strategies to properly respond to patients’ distress and dying.
CHAPTER II: REVIEW OF THE LITERATURE ABOUT
THE THREAT OF MORTALITY FROM THE PERSPECTIVE OF
CANCER PATIENTS

God grant me the serenity
To accept the things I cannot change,
Courage to change the things I can,
And wisdom to know the difference.

(Untitled prayer that later became known as the Serenity Prayer, generally attributed to Reinhold Niebuhr, 1934.)
In this chapter, I critically review the literature about the threat of mortality and death from the perspective of cancer patients. The purpose of this review is to provide an understanding of patients’ existential distress, as well as its impact on health-related quality of life for them and their families. Due to the limited amount of literature targeting existential distress of patients undergoing bone marrow transplantation (n= 9 studies), I expanded my review to the existential distress of cancer patients in general, before focusing on patients in bone marrow transplant units. I organized the chapter to follow the trajectory of cancer to uncover a sense of how the threat of patients’ mortality occurs potentially independent of patients’ prognoses. Additionally, this review substantiates how the threat of patients’ mortality influences relationships with family caregivers and health care providers.

Themes Reflecting the Threat of Patient’s Mortality and Death with a Cancer Diagnosis

The review identified four themes reflecting patients’ perspectives about the threat of mortality and death: 1) equating death with a cancer diagnosis, 2) sequelae of cancer that trigger fears of death, 3) the impact of the threat of mortality on health-related quality of life, and 4) responses of family caregivers: a shared threat of mortality.

Equating Death with a Cancer Diagnosis

Patients with a cancer diagnosis equate it to a possibility of death in which they are aware of being “consciously thrown” into an experience of dying [sometimes described as into “darkness;” (Lane, 2005)] as a probable reality in their future (Albaugh, 2003; Arman & Rehnsfeldt, 2003; Cohen & Mount, 2000; Landmark, Strandmark, & Wahl, 2001). Studies indicate that following a diagnosis of cancer, a sense of worry stems from newly felt responsibilities and experiences which include: to fight a perceived vulnerability to death
(Arman & Rehnsfeldt, 2003; Landmark et al., 2001; Lee et al., 2005); to manage an uncertainty about the future (Chochinov, et al., 2002; Farrell, Heaven, Beaver, & Maguire, 2005; Landmark et al., 2001; Lee et al., 2005); to deal with fears of an inability to do things (Chochinov, et al., 2002; Farrell et al., 2005); to have concerns of being a burden to the family (Kelly et al., 2004; Mak, 2005); to have doubts about treatment and its side effects (Chochinov, et al., 2002; Cohen & Ley, 2000; Griffiths, et al., 2002); to experience marginalized feelings of being different (Farrell et al., 2005) and to endure unwanted sympathies (Richer & Ezer, 2002), embarrassment, and shame that imprints upon their sexuality and relationships with others (Farrell et al., 2005; Griffiths et al., 2002; Landmark et al., 2001; Richer & Ezer, 2002).

Patients can experience mixed emotional reactions including shock, anxiety, despair, anger, fear, and sadness (Adelbratt & Strang, 2000) that temper different degrees of ambiguity in relation to "not wanting to know," while on the other hand wanting to be told of their prognoses. The awareness of a shortened life and dying fluctuates from suspended awareness or denial, uncertain, partial or ambiguous awareness, to active and open awareness (Johnston & Abraham, 2000). Patients commonly try to “calculate the odds” to judge the appropriateness of being optimistic or hopeful, and “play the odds” to portray prognostic information in a relatively favourable light (Thorne, Hislop, Kuo, & Armstrong, 2006). However, even when the awareness of death is kept at a discreet distance, complete and total denial is uncommon (Adelbratt & Strang, 2000; Sand, Olsson, & Strang, 2009). Prognostic denial is reported to most likely arise in patients with underlying psychological distress and emotional turmoil and is associated (more often in men than women) with the prevalence of depression three times greater than those with partial or complete acknowledgement (Chochinov, et al., 2000). Existential distress may also manifest as physical discomfort, insomnia, and panic attacks (Grant et al., 2004), and is often attributed to fearing that hope will not be offered, or that others, such as health care providers will "give up" on them (Kirk, Kirk, & Kristjanson, 2004; Wenrich et al., 2001).
Perhaps more than any other illness, a diagnosis of cancer is a culturally taboo topic, often creating existential distress in patients (Friedrichsen, Strang, & Carlsson, 2000; Kirk et al., 2004), caregivers (Kirk et al., 2004; Takesaka, Crowley, & Casarett, 2004), and health care providers (Costello, 2001; Friedrichsen et al., 2000; Takesaka et al., 2004). In a study by Sapir et al., (2000), 92% of patients indicated that they wanted disclosure of “bad news,” while 6% wanting bad news conveyed to their families but not to themselves. For those that wanted the bad news conveyed to them directly, 78% wanted information conveyed gently and sensitively, and 14% wanted the information given without regard to their emotional response, (Sapir, et al., 2000). In a phenomenological study of cancer patients (n=10), receiving “bad news” put them on a journey of continual adaptation in a series of processes. Initially patients experienced suspicions of their life-threatening diagnoses, which when others (caregivers and health care providers) tried to dismiss or minimize only further augmented their level of anxiety. Patients’ knowledge of their cancer diagnoses “surfaced” when their suspected-knowing was validated and their sense of being given a label challenged their sense of existence. Still, even after accepting their diagnoses, a sense of anxiety remained central to patients living with uncertainty (Tobin & Begley, 2008). The latter study reflects a process in which patients may express more anxiety when the uncertainty of a life-threatening diagnosis is probable rather than certain (Hinton, 1999).

One such instance in which death seems probable, rather than certain is in patients considering whether to undergo bone marrow transplantation. In a study of 213 multiple myeloma patients undergoing diagnostic evaluation for autologous stem cell transplantation, 33% exceeded cut-off scores for general emotional distress. Of these, 34% had clinically elevated levels of anxiety and 24% reported significant depressive symptoms (Sherman, Simonton, Latif, Spohn, & Tricot, 2004). Hence, despite trends to provide full and open disclosure to patients about their cancer prognosis, research about “breaking bad news” supports
"conditional" disclosure. This means "titrated" or "graduated dosages of truth" are conveyed to patients to support negotiating a sense of control of their experiences, depending on age, education, and sex of the patient (Field & Copp, 1999, Parker, et al., 2001).

Sequelae of Cancer that Trigger Fears of Death

The meanings given to living with a cancer diagnoses differ among individuals. In an exploratory survey of 58 long-term cancer survivors (diagnosed at least 5 years earlier), Foley et al., (2006) found that participants reported four different meanings (sometimes in combination) in response to their cancer: "that's life;" resentment; relinquishing control; and personal growth. Participants (more often male) interpreted the experience as "that's life," meaning that current quality of life had little to do with cancer or its treatment because they adjusted by "compartmentalising" it, and as so, could perceive themselves as having a good quality of life and feeling "no change of lifestyle" but "happening to have cancer." On the other extreme, some individuals expressed frustration and resentment about having cancer. They felt that cancer (and its treatment) intruded upon their future with its possibilities of physical deformities and health problems. They experienced residual pain, shifts in identity, and social isolation, which led to significantly reduced quality of life. Some people expressed meanings of "relinquishing control" of parts of their life that had to be let go due to it "being their fate" and "having no control."

Lastly, others (more often women) found meaning in a felt "personal growth" that amplified pre-existing inner strength and a greater appreciation for life (Foley et al., 2006). Thus, patients express feeling different degrees of being prepared physically and emotionally to cope with the fear of the unknown, particularly the fear of death (Cohen & Ley, 2000).

Additionally, individual differences related to coping with cancer are associated with family history or previous trauma. For instance, Esplen, et al., (2003) found a significant association in a subgroup of colorectal cancer patients with current depression or anxiety.
symptoms who had endured losses to cancer. This subgroup of patients anticipated becoming increasingly more depressed after results of a forthcoming genetic test for the presence of a genetic mutation. Although the distress associated with being at risk for cancer may not be the same as distress that occurs with a diagnosis or advanced disease (Jones, Huggins, Rydall, & Rodin, 2003), Esplen's study demonstrates that meanings given to life with a possible future with cancer are altered when past experiences colour present meaning.

According to Carter, MacLeod, Brander, and McPherson et al., (2004), a cancer patient’s agency depended on his/her ability to define and actualize his/her needs. The ability to take charge or exert some agency over life was an overarching and recurring existential theme in patients with cancer (Carter et al., 2004; Volker, Kahun & Penticuff, 2004). Often patients attempted to control the timing and amount of information received from clinicians. Some patients wanted less detail about prognosis in the later stages of their illness as compared to earlier stages. They chose to focus more on routines of daily living, while their families continued to meet separately with health care providers about details of prognoses and decisions about care (Kirk et al., 2004). In these studies, personal control over the dying process meant being able to regulate information to support functioning and comfort related to existential distress (Carter et al., 2004; Volker, Kahn & Penticuff, 2004).

Cancer patients express a need to feel connected with significant others and health care professionals to enhance their emotional and spiritual well-being (Friedrichsen et al., 2000; Grant et al., 2004; Griffiths et al., 2002; Lin & Bauer-Wu, 2003; Mak, 2005; Mok, Chan, Chan, & Yeung, 2002). However, some patients may withdraw and/or distance themselves as a way to cope (Johnston & Abraham, 2000). Patients also may experience guilt to varying degrees about regret or sadness placed on others, unresolved conflict in relationships, or concerns of leaving others (Bolmsjo, 2000). Hence, unmet relational needs may exist for many individuals who live a protracted and unpredictable illness.
Fears of death seem located in part from the inability to control one’s bodily integrity. Physical symptoms are a significant part of the burden of a cancer illness, as symptoms signal the reality and remind patients of their illness (Ohlen, Bengtsson, Skott, & Segesten, 2002). Additionally, greater treatment intensity causing physical symptoms may not only trigger additional stress responses but may impact on previous meanings accumulated about the nature of the threat of mortality (Gurevich et al., 2002). Hence, by controlling symptoms of illness or treatment, cancer patients may keep the awareness of death at a discrete distance (Sand et al., 2009).

Culturally embedded ideas of order and boundaries construct social relationships (Lawton, 2000). According to Lawton's (2000) ethnographic study in England of patients in a hospice, the loss of the patients’ bodily agency and capacity for "self-containment" of bodily fluids and odor diminished their sense of self and identity in society. Some patients were uncomfortable when their bodies began to disintegrate. The breakdown of their body's “boundedness” was accompanied by the emission of specific smells (i.e., odor of excreta, vomit, and rotting flesh) that became distressing and humiliating to patients and their families (Lawton, 2000).

Individuals who face awareness of their heightened risk of death may fall from their protective illusions of an intimate and private body into social sequestering their body to public gaze for bodily control. Lawton (2000) theorized that one’s agency is given partially to others for whom they become the source and/or means of the patient's bodily actions. Cancer patients sometimes express feelings that they do not have control over anything (Cohen & Ley, 2000). "Agency becomes located in the bodily actions themselves and the carer's self often extends into the body of the 'dependent' patient she or he is tending to and moving around" (Lawton, 2000, p.108). The carer's own self is suggested to become assimilated into the "body-object" of the patient and self, and subjectivity may extend beyond parameters of the "individuated" body.
Hence, the conception of the self is no longer located inside the body, but on the contrary, is socially dependent to encompass the external health care system—nurses,' physicians,' and family caregivers’ selves for their agency, bodily containment, and habitus. The impact upon the health care staff's sense of self was described in Lawton's (2000) study as one where the patient became an "object" closely enmeshed with staff’s own sense of self. As the possibility of the patient as a social person deteriorated, the patient became objectified as a heavy "weight" rather than as a "whole" person, for which formal and informal caregivers gradually assumed the burden for increasingly more of the patient’s agency (Lawton, 2000).

Lawson's (2000) study was in a hospice with people who recognized that they were at the very end of life, but there may be moments wherein physical symptoms, such as pain and fatigue, or a sudden change in physical symptoms, causes considerable existential distress in patients not considered “palliative.” For example, newly admitted cancer inpatients report common physical symptoms of a lack of energy (71%), pain (54%), drowsiness (45%), dry mouth (40%), and nausea (38%; Jones et al., 2003). Although pain intensity alone does not predict the desire for a hastened death, the amount of interference as a result of pain on general activity (including mobility), mood and ensuing fatigue, is significantly associated with hopelessness (Jones et al., 2003). Hence, it makes sense that nurses report that patients who are acutely ill and in need of intensive nursing care have significantly more psychological distress associated with depression and/or anxiety and delirium (Pasacreta & Massie, 1990).

The site of a cancer disease (Mystakidou, et al., 2005), stage of illness (Farrell, et al., 2005), time since diagnosis, and age and sex of a person (Lee, et al., 2005) can commonly influence the severity of suffering and types of concerns a person will experience at any one moment in the process of his/her illness. In a study of 121 people treated for colorectal cancer, by Klemm, Miller, and Fernsler (2000), the time since treatment, perception of illness severity, and activity level accounted for 45% of variance in a self-reported instrument to measure
demands of illness. Demands of illness were perceived greater and more distressing in people treated for their illness within two months, who perceived their condition to be unsure or terminal, who reported greater impairment of activities, and who were in the younger age group (26-45 years old). The 10 most intense illness-related demands were reported to be existential concerns. These included: how long they might live; the value of their life; if their illness was spreading undetected; questions about how their family would cope in the future; their own mortality; worries that the illness would involve other body parts in the future; questions around control of their illness in the future; worries that their illness may reoccur with its initial severity; worries they would develop new physical symptoms in the future; and concerns that their children would face the same illness (Klemm, Miller, & Fernsler, 2000, p.637).

Existential distress may be a result of how individuals cope with multiple, prolonged and intermittent experiences in hospitals. For instance, waiting for results of diagnostic tests is one of the most stressful experiences (Gurevich, Devins, & Rodin, 2002). Even the smell of a hospital can trigger intangible death anxiety (Adelbratt & Strang, 2000). Though, most patients try to avoid fears of death in their everyday life, the literature suggests that the daily routines, exposure to suffering of others, and even innocuous smells and sights in a hospital may predispose inpatients to live with a constant threat and anticipation of encountering death (Gurevich, et al, 2002).

In order to cope with the ubiquitous nature of the threat of mortality, some patients seek strategies that can help emotionally distance themselves from fears of dying, yet sometimes accept the intellectual idea of being near death to enrich an appreciation for everyday moments in life. Cancer remains a trespasser in their bodies and is synonymous to death as the “enemy,” “scary” and “unreal.” Yet, the proximity to death gives some patients a new zest that helps them re-prioritize values in their lives to moments in the present (Adelbratt & Strang, 2000). The altered meanings given to "life" and "living with cancer" are described in studies (Arman &
Rehnsfeldt, 2003; Lane, 2005; Richer & Ezer, 2002; Yedidia & MacGregor, 2001) in which patients tell stories of "moving on" or reconstruct a new reality of living within a “will to live differently.” For example, in a qualitative study by Richer and Ezer (2002) of 10 women receiving chemotherapy for the first time for breast cancer, dimensions of "living in it" (an intrapersonal dimension), "living with it" (an interpersonal dimension), "getting there" (a process of learning), and "moving on" meant seeking a new balance and discovering "how it all fit in their existence." Given that physical symptoms were tolerable and stabilized, a meaning of “transcendence” evolved over time. A process of being able to "move on" or experience "transcendence" gave these women a deeper meaning of life in their situation, particularly in the beginning of the experience and later in ways that allowed them to face questions of recurrence which persisted (Richer & Ezer, 2002) and did not necessarily abate with time (Cohen & Ley, 2000).

A search for meaning, peace, or a guide into the unknown can be especially helpful during events that create overwhelming psychological and existential concerns. Grant et al.'s, (2004) qualitative study of 20 cancer patients in Scotland found that patients searched for meaning at the point of the diagnosis of cancer, or when acute illness symptoms incapacitated them. They searched for peace of mind and freedom from a "dark" and often nightly fear of dying. Furthermore, they searched for a guide into the unknown to help them make sense of their living through a dying experience (Grant et al., 2004). Still in other situations, rather than talking about difficult feelings, some patients may want to talk about their normal lives, their hobbies, and their families, as a way to help them find meaning and hope (Kvale, 2007).

Today, there is growing interest about how awareness of mortality impacts feelings of meaning and hope (Curtis, Wenrich et al., 2002). Hopelessness is the loss of an attachment to hope (Mystakidou, et al., 2009) and is associated with a loss of meaning and purpose in one’s life (Chochinov, et al., 2000). When hope is lost, notions of risk are evident. In a study of inpatient
cancer patients (n= 224), hopelessness was a mediator and independent factor significantly predicting a desire for hastened death. Of those participants who reported greater hopelessness and advanced disease, 7% scored in the moderate range for a desire for hastened death and 2% in the high range for a desire for hastened death (Jones, Huggins, Rydall, & Rodin, 2003). In a larger Canadian sample of adult ambulatory patients with metastatic cancer (n= 1,014), 23% reported hopelessness (Rodin, et al., 2007). While depression and hopelessness were found to be mutually reinforcing, hopelessness had a greater relative influence and independently predicted and mediated effects of psychosocial distress and disease-related variables on the desire for hastened death (Rodin, et al., 2008). These findings suggest that existential distress for some is significantly associated with hope (or hopelessness) of an anticipated future given to interpretations of life with cancer.

Many patients appear to maintain hope despite knowing the terminal nature of their illness (Clayton, et al., 2007). Hence, hope is not necessarily terminated with the increased awareness of certain death, although it appears to take on different appraised meanings in comparison to life prior to cancer. Hope can maintain traditional meanings of restorative curing (Johnston & Abraham, 2000) and longer life, but can also apply to ways patients may maintain control of their lifestyle through relief of pain or access to supports to have a peaceful death (Kirk et al., 2004). Appraised meaning appears to fluctuate as the illness progresses (Kirk et al., 2004) and lends itself towards changing attitudes of continued living in experiences of the threat of mortality and dying (Lee et al., 2006; Richer & Ezer, 2002). To put it another way, living “against the odds” or longer than expected reassured patients that they were among the small percentage that had positive effects from treatment or beat the clinicians’ “pessimistic predictions” (Thorne, Hislop, Kuo, & Armstrong, 2006, p. 326). Hope appears to be a central construct in light of how it mitigates fears of dying and death (Lin & Bauer-Wu, 2003).
Living with hope while dealing with a cancer diagnosis challenges individuals to continually integrate contradicting meanings of the threat of mortality, so that they inherently adapt to living differently with cancer. For patients undergoing bone marrow transplantations, living differently may be both concrete and embodied in experiences of: being far from home, dependent on health care professionals as strangers, living with risks associated with effects of aggressive treatment on one’s body, and possibilities of their primary disease relapsing (deCarvalho, et al., 2000). In efforts to cope, bone marrow transplant patients reframe survival statistics to allow for some measure of control and optimism over what to expect and sometimes extrapolate from prior experiences (Haberman, 1995). In a sample of 20 adult survivors of autologous bone marrow transplantation, the bone marrow transplantation was perceived as their last choice for having maintained future hope of survival. Yet, while the treatment provided some control over ridding themselves of the cancer, many still felt frightened due to being unprepared physically and emotionally for the anticipated risks of death and side effects of the aggressive treatment. Many of the patients reported feeling “worse” when their emotions were not recognized by health care providers and even felt “a need to suppress” their emotional experience because of others' expectations that they not show fear (Cohen & Ley, 2000). On bone marrow transplant units, patients’ perceived expectations from medical and nursing staff were critical due to their sense of extreme dependency on them. Physicians were perceived to control the treatment, while nurses to coordinate daily care routines (Haberman, 1995). "Nurses' authority was fundamentally indisputable" (p.902) and many patients felt compelled to form close relationships with nurses in order to be able to negotiate control and optimism in their everyday care (Steeves, 1992).
The Impact of the Threat of Mortality on Health-related Quality of Life

Traditionally, health-related quality of life has focused primarily on aspects of physical functioning to compare different treatments and to a lesser extent, to meanings of existential or spiritual concerns (Kassa & Loge, 2003). However, there is accumulating evidence that health-related quality of life is a complex concept that involves not only physical well-being, but emotional, psychological, social, and spiritual well-being (MacDonald, 2001; Sahlberg-Blom, Ternestedt, & Johansson, 2001, Balfour, Boston, & Cohen, 2007; Mystakidou et al., 2007). In a phenomenological study by Mount, Boston, and Cohen, (2007), finding deeper meaning through suffering, and the experience of connectedness were recurrent themes of 21 patients with cancer or other life-threatening illnesses. Hence, existential distress as a component of suffering is postulated to be an area for therapeutic activity to improve health-related quality of life (Pelletier, Verhoef, Khatri, & Hagen, 2002).

Currently, health-related quality of life is being conceptualized more holistically to include existential issues in an individual's capacity to continually renegotiate and renew their sense of integrity and wholeness, particularly when experiencing erosion of their subjective self related to their illness. A personal sense of self (as historical and social) is tied to one's attitude to the world (Whitehead, 2003). Suffering is generated from a loss of self and the meaningful things in the world perceived to be lost (Gregory & Russell, 1999). Regardless of perceived life expectancy, greater existential well-being was associated with less distress and better quality of life in 103 cancer patients in the United States. A series of correlations and analyses of variance found no difference in demographic factors (i.e., ethnicity, age, gender, marital status, and religious orientation) nor in medical factors ([cancer type, time since diagnosis, and treatments received] Laubmeier, Zokowski, & Blair, 2004).

In a qualitative study by Adelbratt and Strang (2000) with 20 patients (mean age of 44 years) with malignant brain tumors, the construct of existential anxiety was acknowledged as
coming from a sense of annihilation of their sense of self, sometimes expressed in patients' quotes: "I am afraid of vanishing away, and I think of that several times a week; I panic, one day I will just disappear and cease to exist" (p.503). The study indicated that suffering can be a prolonged and cumulative form of existential pain, described as "a painful acknowledgement of the inevitable" (Adelbratt & Strang, 2000). The idea of a "slow" death was frightening as individuals imagined a kind of "fading" away as they lost their autonomy (Adelbratt & Strang, 2000). Although existential distress includes multiple symptoms, such as hopelessness, dependency, and loss of dignity, the distress culminates to a sense of meaninglessness, suggested to be the essence of existential distress (Morita et al., 2000).

In a qualitative meta-synthesis by Arman and Rehnsfeldt (2003), patients with breast cancer revealed a process by which regaining a balance and wholeness of person meant renewing values and priorities in life and integrating and accepting death within notions that involved spirituality and an enhanced sense of meaning in life. Patients voluntarily entered into conflicts between hope and hopelessness, meaning and meaninglessness, life and death in a struggle to find a way to give their suffering meaning and re-integrate a sense of dignity (Arman et al., 2003). Halldorsdottir and Hamrin (1996) in Sweden consistently found existential changes in patients' sense of what was previously "normal." Post-treatment cancer patients (n=9) expressed re-defining their identities in new understandings of a future with uncertainty and felt vulnerability to reoccurrence of cancer. Also, a sense of isolation changed their perspectives. Kuhl's (2002) qualitative research about the lived experiences of people with cancer or AIDS revealed that their illness altered social roles and relationships in ways that created a sense of isolation. They "felt 'out of touch' physically and emotionally" (p.100) in their illness. There was a strong need to be physically touched by another person and to be emotionally connected with those who cared for them and who were involved in their care (Kuhl, 2002).
If restitution to one's sense of being "normal" cannot be fully achieved, the desire for many people with cancer, therefore, may be toward a quest for meaning of potential triumph that simultaneously endures, surrenders to, and transcends the illness experience — an experience that for some is hoped to restore dignity and reconnect them with others and/or something larger than themselves to provide them a sense of comfort of not being alone (Albaugh, 2003; Landmark et al., 2001; Lane, 2005; Yedidia & MacGregor, 2001). In trying to find a new balance in their lives, the quest for meaning is sometimes unfulfilled, and some describe volatile experiences due to unresolved loss and resignation to a disease that engulfs them (Yedidia & MacGregor, 2001).

In part, aggressive treatment may contribute to the trauma of patients’ experiences and may hinder their capacity to reconstitute a “normal” quality of life. For example, in a pilot study by Lee et al., (2005) with adults admitted for bone marrow transplantation, patients reported varying amounts of distress fluctuating with the treatment phases. Autologous and allogeneic patients reported emotional distress before transplantation to be significantly worse in the areas of social functioning, vitality, emotional and mental health, and overall mental functioning. Post-transplantation distress was greatest for patients with emotional issues (25%), whom were more likely to take prescription medication for anxiety, depression, and sleep disturbance (Lee et al., 2005).

Responses of Family Caregivers: A Shared Threat of Mortality

Studies indicate that family caregivers shared a threat of mortality with patients (Juarez, Ferrell, Uman, Podnos, & Wagman, 2008). Families' concerns about prognosis were similar to those expressed by patients (Hinton, 1999). For example, family members maintained hope, and tolerated levels of uncertainty related to the patient's prognosis (Johnston & Abraham, 2000). Family caregivers experienced moderate to severe amounts of stress and fatigue in their daily
schedules (Aranda & Hayman-White, 2001), often struggling daily to protect the patient's autonomy, while ensuring the patient's safety and health (Mangan et al., 2003). Juarez et al. (2008) measured the impact of palliative surgery on quality of life for family caregivers of patients with advanced cancer. The prospective cohort study reported that the most negative factor across time was caregivers’ uncertainty about patients’ futures. Caregivers’ sense of uncertainty improved slightly at 3 weeks post-operatively, but declined at two and three months with caregivers having more uncertainty than patients themselves (Juarez et al., 2008).

Given the families' physical, emotional and social connections to the life-threatening nature of their loved one’s illness, it is not surprising that depression of caregivers is linked with greater awareness with patients' deteriorating prognoses (Hinton, 1999). Relatives generally reach acceptance of their loved ones' dying sooner than patients, particularly when the patient is over 70 years old and family witness deteriorating physical weakness and quality of life in the patient (Hinton, 1999). Having said this, families often worry about revealing their true emotions and concerns with the patient due to fears it might be an added burden (Mangan et al., 2003). Some spouses express survivors’ guilt, or express feelings that they could also die, even claiming they might die before the ill partner (Adelbratt & Strang, 2000).

Family caregivers report impediments to receiving supportive care from the health care system. While nurses are found to have profound impacts on families coping with critical illness, some are reported to not respond to the emotional needs of the family (Eggenberger & Nelms, 2007). In addition, family members often experience difficulty absorbing and retaining information, experience inappropriate timing of information and support, and have concerns about bothering health professionals whose resources are limited due to time constraints (Dunne & Sullivan, 2000; Hudson, Aranda, & Kristjanson, 2004). Younger family caregivers tend to describe greater distress that is hypothesized to stem from a rapid and/or unexpected decline of their loved ones they are caring for (usually young as well) and insufficient time and preparation
to grieve (Takesaka et al., 2004). Additionally, women and those caring for patients at diagnoses and end-of-life stages express greater amounts of emotional distress (Harding & Higginson, 2003).

For some families, the acute hospital setting is perceived as an incongruous place for loved ones to die, often evoking feelings of helplessness, loss of control and frustration, and an inability for them to perform their usual roles, associated with caring for their loved one (Dunne & Sullivan, 2000). Family members can experience the hospital environment as “rushed” and “hurried,” and the culture to be based on "quickness" to find beds for acutely ill people, rather than attend to someone who is recognized to be terminally ill (Dunne & Sullivan, 2000).

Patients with cancer report that social support is the strongest correlate to their sense of global meaning whereas high levels of existential distress are related to lower levels of global meaning (Lethborg, Cox, and Kissane, 2007). The importance of bolstering and ensuring social support from and for family caregivers has only been recently acknowledged and valued by health care providers (Mok et al., 2002). Thus, more research is needed to understand strategies to empower family caregivers to obtain and receive information and to tolerate their proximity to a shared threat of mortality.

One such strategy to empower families is suggested by an Australian study in bone marrow transplant units (McGrath & Holewa, 2007). Findings of the study suggest that families suffer significantly as a result of continuing dependency on hospital treatments to prolong patients’ lives. Treatments can continue over many years and recent suggestions advocate for the relief of families’ suffering by enabling blood products to be provided in other places, other than the hospital, such as the home (McGrath & Holewa, 2007). Research exploring whether or not this strategy restores families’ sense of agency and reduces their suffering with patients is needed.
Discussion

The strength of the review is the evidential support for the argument that all individuals experience suffering as the threat of mortality when they are diagnosed with cancer, which fluctuates but endures throughout the cancer trajectory, irrespective of their proximity to death. Cancer carries a stigma of being unable to control the inevitability of death. Existential distress continues to be exacerbated by triggers related to diagnostic assessments, treatments, and even characteristics of the hospital itself, like the innocuous smells and sights arising from continuous intravenous blood products and steroids associated with bone marrow transplantation. Cancer patients experience existential fears of death fueled by isolation, meaninglessness, a loss of will to command their agencies, and the inability to be responsible for controlling their bodies, all of which impact their health-related quality of life and can augment a desire to wish a hastened death. Additionally, families share the existential distress of patients. Often existential needs of patients are not being met and can create a propensity for patients and families to experience helplessness and hopelessness, which mutually reinforce psychiatric symptoms and mood disorders.

Additionally, this review shows evidence that health care providers, and particularly nurses and physicians, influence patients' outcomes, based on their communication and their tone of care. However, despite an approach to cancer care that would benefit from including existential care, the weakness of the review is the lack of understanding about how health care professionals are, or are not, actively attending to the threat of mortality in ways that are therapeutic for patients and their families. The avoidance to talk about concerns surrounding life’s finiteness is in part associated with findings in the literature that the threat of patients’ mortality tends to only occur when there is an acknowledgement of dying and when resources exist to refer to palliative end-of-life care.
Summary

The empirical literature supports that the sources of cancer patients’ existential distress originate from fears of death and dying, their sense of existential isolation, anxiety and responsibility about freedom to create their lives, and their sense of meaninglessness and loss of purpose. Patients’ emotional distress fluctuates throughout their illness trajectory, but may continue to escalate when they do not have opportunities to validate and share their fears with their health care providers. It is incumbent upon formal caregivers to be aware of and respond to patients’/families’ existential distress, particularly when treatment carries a significant perception of risk and therefore, the potential loss of hope.
CHAPTER III: REVIEW OF THE LITERATURE ABOUT
THE THREAT OF MORTALITY AND ONCOLOGY NURSING

The Plight of Nursing

I am the “Lady with the Lamp.”
A stranger moving in and out of your world shadow-like

I brush the edges of your fear, leaving some of myself behind

Sometimes at the end of my shift, I cannot account for all of me.

I retrace my steps, in hopes of putting myself back together again.

By Carol Battaglia (January, 2009)
The purpose of this literature review is to explicate knowledge about cancer nurses’ experiences with patients facing the threat of mortality. Empirical knowledge of existential care is in the early phases of its conceptual formation and there are only minimal studies exploring cancer nurses’ experiences, let alone cancer nurses in bone marrow transplant units (n= 4). Therefore, it was necessary to include other settings where cancer patients receive care, such as intensive care, nursing homes, or medical settings. The literature search focused on studies about cancer clinicians describing psychosocial aspects of supportive care. However, only approximately 10% focused specifically on aspects of existential issues. As such, I examined studies about preparing for and moving through transitions from curative cancer treatment to palliative end-of-life care. Admittedly, most of this literature was within palliative end-of-life care, and so it was also included.

Studies (n= 122), excluding 10 literature reviews, varied within country of origin and type and experience of clinicians. Thirty percent originated from the United States, while the other 70% took place in other countries, including 21% from the United Kingdom, 8% from Canada, 8% from Sweden, and the remaining from Australia, China, Scotland, Ireland, Japan, Netherlands, Greece, Spain, Brazil, Israel, Finland, and New Zealand. The majority of the participants were female clinicians, and usually oncology nurses or palliative care nurses (87%). Physicians were the focus of five studies, but 11 included combinations of other disciplines (i.e., psychologists, counselors, occupational therapists, dieticians, chaplaincy, and administrative health care staff).

Additionally, perspectives from undergraduate nursing students being prepared to care for dying people (n=6) were included. The front-line clinicians' average years of work experience ranged from 2 months to at least 5 years. In the studies with specialist palliative care clinicians, the average years of work experience ranged from a minimum of 2 to 35 years. Four studies had samples of both general and specialist clinicians in the acute hospital setting.
Although some of the studies did not report the age of health care providers, those that did, reported a range from 21 to 55 years old.

Themes Reflecting Cancer Nurses’ Existential Care

*Four themes* highlight nurses’ experiences of caring for cancer patients who face the threat of mortality: 1) cancer nurses’ engagement with patients’ existential concerns, 2) the organization of cancer nurses’ existential care, 3) cancer nurses valuing patients as persons within issues of mortality, and 4) the embodiment of cancer nurses’ existential care.

Only four studies in the context of bone marrow transplant units explored cancer nurses’ experiences and their clinical knowledge of care (Aranda, 2001; deAraujo, et al., 2004; McGrath & Holewa, 2007; Molassiotis, & Haberman, 1996). These studies are described under each theme, after a general exploration in relation to cancer nursing.

*Cancer Nurses’ Engagement with Patients’ Existential Concerns*

Given that conversations about death are challenging and often upsetting, an assumption has been that educating clinicians to "talk" about death will decrease their avoidance and build their confidence in entering into these conversations. In Western culture, health care communication is fundamentally assumed to empower patients/families with information to make decisions and support them to realize a clinically "good" or “personally ideal” death (Degner, Gow, & Thompson, 1991; Dunne et al., 2005; Hamilton & McDowell, 2004; Heaven & Maguire, 1996; Kristjanson et al., 2001; Lin & Bauer-Wu, 2003; Sheldon, 2005; Wilkinson et al., 2002; Wright, 2001). Educating nurses about how to talk to patients and families about dying, as well as the recognition of impending death has been identified as needed areas for more competence and proficiency (White, Coyne, & Patel, 2001). When clinicians demonstrate poor communication, there is a significant cost to the patient/ family, and service delivery system in
The clinicians’ ability to assess and to discuss the patients’ fears of dying and death, sensitively attuned to "the right time and way" appears extremely important to avoid augmenting the patients' suffering. Indeed, existential care may be more about communication skills that continuously questions rather than provides fixed or final answers (Surbone & Baider, 2009). This challenging issue was alluded to in the following studies (Taylor & Mamier, 2005; Taylor, 2003) where cancer patients expressed spiritual needs from nurses, but the appropriate approach was not self-evident. Some patients wanted nurses to make use of humour, help them have quiet time or space for reflection, or share private prayers with them (Taylor & Mamier, 2005). In the other qualitative study, nursing spiritual care included a felt connection with nurses' presence, listening, talking about feelings of uncertainty, sharing prayers, and mobilization of spiritual or religious resources to inspire hope (Taylor, 2003). The patients' dissatisfaction or clinicians' difficulty engaging in existential care may result in distancing as the main coping strategy that contributes to further emotional distress (Kelly et al., 2004), and in turn may augment distress for those that care about them (Dunne & Sullivan, 2000; Dunne, Sullivan, & Kernohan, 2005; Johnston & Abraham, 2000; Takesaka et al., 2004).

In a literature review exploring communication training programs by Sheldon (2005), the majority of research studies (n=19) showed statistical improvement in communication skills (especially facilitative behaviors such as open-ended questions and empathic statements) by participating clinicians (including six studies with cancer nurses). More recently, a randomized controlled trial involving 170 nurses in the United Kingdom improved nurses psychological assessment when taught communication skills over 3 days (Wilkinson, Perry, Blanchard, & Linsell, 2008). The training had the greatest effect on emotionally-laden topic areas and a significant number of nurses reported increased confidence and efficacy in communication with
cancer and palliative care patients. Furthermore, patients interviewed by the intervention nurses reported greater satisfaction based on a more positive emotional state than those interviewed by the control nurses. However, 17% of intervention nurses’ skills deteriorated or stayed the same 12 weeks post-course. Moreover, there was no evidence that intervention nurses impacted on patients’ levels of anxiety (Wilkinson, Perry, Blanchard, & Linsell, 2008).

The interpersonal and varied nature of health care provider-patient relationships and how they impact everyday decisions of an existential nature are generally unknown in the health care literature (Hack et al., 2005; Henoch & Danielson, 2009; Parker et al., 2005; LeMay & Wilson, 2008). Practical application of communication skills training in cancer settings has been shown to improve health care providers' confidence and satisfaction with their skills (McClement, Care, Dean, & Cheang, 2005; Butow, et al., 2008) but have shown questionable impact in changing practice patterns. In one study by Brown et al. (1999), there was no improvement in patient satisfaction after physicians completed a standardized communication skills training program (Sheldon, 2005). The latter finding supports another study (Heaven & Maguire, 1996) reporting an overall lack of improvement in nurses' ability to elicit and identify patients' concerns despite increased use of communication skills. Currently, there is evidence that communication skills may support nurses to be more emotionally attuned to patients’ distress, but these skills have not been found to be sufficient to increase the specific detection of psychological distress or to responding appropriately to patients’ distress (Jenkins, et al., 2010).

Patients and providers may differ about what emotional needs are important to attend to in any given situation. In a Swedish sample of 52 nurses and their cancer patients, nurses tended to overestimate patients’ emotional distress and to underestimate patients’ coping resources and quality of life (Martensson, Carlsson, & Lampic, 2007). Another example of mismatched nurse-patient expectations was apparent in a study reporting that the common complaint that nurses desired was more time with patients who were terminally ill. However, the study showed that
time spent with nurses was not significantly correlated with patient satisfaction (Sulmasy & Sood, 2003). Thus, this suggests that rather than simply needing more time with patients, nurses need more *how-to* skills to assess patients’ emotional distress and to activate patients’ coping resources to improve their quality of life.

For most nurses, facilitating communication to prevent or relieve suffering continues to be uncomfortable, perhaps moreover, when patients express feelings that cannot be easily resolved. When undertaking a patient history, some nurses avoid acknowledging patients’ feelings or block rather than facilitate communication (Wilkinson, 1991). Blocking was described in a study by Wilkinson (1991) as "normalizing or responding with stereotyped comments, premature/false reassurance, inappropriate advice, closed/leading multiple questions, 'passing the buck,' requesting an explanation, inappropriate disapproving/disagreeing, inappropriate approving/agreeing, defending, changing topics/ignoring/ selective attention to cues, changing focus to relative, jollying along, and personal chit-chat" (p.679). In Wilkinson's (1991) descriptive survey, psychologists rated participating oncology nurses’ (n= 56) blocking behaviours using tape-recorded nursing histories with three cancer patients: one newly diagnosed, one with a recurrence, and one admitted to palliative care. While findings showed that overall blocking behaviors predominated in nurses (n= 44), they were significantly higher in nursing histories taken with patients who were admitted with a recurrence of cancer, compared to newly diagnosed or palliative care cancer patients (Wilkinson, 1991).

The use of existential skills and techniques may be avoided or constrained by some clinicians due to a variety of personal reasons. There often exists a misunderstanding that a threat of mortality need only be attended to with patients who are religious or at the end of their lives (Orchard & Clark, 2001). However, in a study by Balboni, et al., (2007), 72% of patients (n=230) with advanced cancer reported that their spiritual needs were minimally or not at all supported by the medical system and 47% reported that their spiritual needs were minimally or
not at all supported by a religious community. Additionally, many clinicians do not know how much to tell patients about their diagnosis and prognosis due to a belief that a fully informed patient has the possibility of being led to despair, disappointment, and isolation (Canto, Canaves, Xamena, & Amengual, 2000; Georgaki, Kalaidopoulou, Liarmakopoulos, & Mystakidou, 2002). Furthermore, oncology nurses question whether they should be responsible for providing existential care to terminally ill patients, that is, 48% to 52.5% disagree or are neutral; (Bolmsjo, Hermeren, & Ingvar, 2002; Meraviglia, McGuire, & Chesley, 2003), or find it difficult to identify someone in need of existential care (Milligan, 2004).

Nurses also wonder whose task it is to coordinate palliative care attending to existential issues (Canto, et al., 2000). With the advent of palliative care specialists, there is a question of whether general nurses may tend to rely on palliative care specialists for existential care and focus nursing care on treatment or curative agendas (Willard & Luker, 2005). In a study by Jack, Oldham, and Williams (2002) in England, palliative care specialists were viewed by key hospital stakeholders to encourage dependency in junior nurses and to potentially cause de-skilling of existential care (Jack et al., 2002).

If oncology nurses do not take the opportunity to attend to existential issues, the literature indicates that the nurses' own integrity and meaning of this kind of work might be devalued and nurses would lose their sense of agency to continue to provide existential care—care articulated to be primarily nurses' everyday responsibility (Davies & Oberle, 1990). To date, while there is considerable literature about the technical and instrumental aspects of communication to assess patients’ emotional distress, there is a lack of empirical research that goes beyond these kinds of skills or to their impact on patients. In particular, the gap is in critical ingredients of the communication process that are responsive to the context of nurses situated in complex inter-professional and patient/family relationships.
Currently, conceptual frameworks of patient-professional communication by Feldman-Stewart, et al., (2005) and dignity-conserving care by Chochinov, et al., (2002) theorize that the clinicians' attitudes and messages they convey impact patient outcomes. Thorne and colleagues (2008) made a compelling argument to this effect in cancer care contexts. They examined individual accounts of 69 patient interviews and 13 focus group participants in an interpretive descriptive study. Poor or unhelpful communication was associated with psychological distress, sense of dehumanization, and despair in patients. In a study analyzing self-report questionnaires, lack of physician training to provide psychological counseling was associated with more patients reporting a wish to hasten their death (Kelly et al., 2004).

The literature suggests that patients may be emotionally harmed by health care providers who hold negative attitudes in the context of their work setting. In a study in Ireland of 73 medical and surgical nurses who cared for cancer patients, 90.4% agreed there was still much that could be done for terminally ill patients, but held negative attitudes about issues of mortality and patient capacity to be prepared and accepting of death (McCaughan & Parahoo, 2000). Pessimistic attitudes were supported by another study (also in Ireland) that only 8.2% of nurses (n=147) believed that the hospital was ideal for managing people with terminal illness due to problems dealing with psychosocial issues (McDonnell, Johnston, Gallagher, & McGlade, 2002). One study even suggested that the use of psychosocial skills depended on nurses’ attitudes about what shift (daytime or night shift) it was deemed appropriate (Roman, 2001).

A model of significant variables predicting which nurses blocked patients to elicit existential issues was found to be: a ward ideology not conducive to open communication between clinicians and patients, absence of religious beliefs, lower level of self-awareness of verbal behaviours (i.e., if nurses were unaware of blocking, they blocked patients more frequently), greater fear of one’s own death, low level of anxiety after completing what appeared to be the most difficult nursing history (i.e., a patient history admitted with recurrence), more
time spent on interests outside of work (up to eight hobbies), and a pattern of frequent conflicts with colleagues. These variables accounted for 61% of blocking behaviours (Wilkinson, 1991). To note, while absence of religious beliefs was one variable that was linked to nurses’ blocking behaviours, Wilkinson’s interpretation of this finding did not account for whether participants’ religious beliefs existed separate from their religious practice/affiliation or whether participants understood these to be synonymous.

Supervised clinical practice in combination with education of a palliative approach has been used with nursing students to modify death anxiety and attitudes to caring for the dying. In a longitudinal quasi-experimental study by Degner and Gow (1988), three separate groups of undergraduate female students in Canadian Universities were compared for their different approaches to education about palliative care: i) nursing students who received a required course and clinical supervision in palliative care in their junior year (n = 102), ii) nursing students who received integrated palliative education (but no clinical supervision) throughout a 4-year program (n = 94), and iii) home economic students who received no palliative education (n = 73). All the students were tested before entering their junior year (the level at which the required palliative course was placed), at the end of their junior year, and 1 year post-graduation. Nursing students given a palliative course and clinical supervision in their junior year and who reported high levels of death anxiety at pre-test time had greater reductions in death anxiety than the other nursing and non-nursing groups. Unfortunately, there was no difference in death anxiety one year post-course graduation between the two nursing groups. The researchers suggested a possible maturation effect due to nursing clinical experience by the end of their 4-year program (Degner & Gow, 1988).

To complicate the matter further, prior experiences may sensitize one to be more conscious of death anxiety. Studies describe death awareness imprecisely and it is unclear whether educational interventions distinguish between one's fear of one's own death, one's fear of
another's death due to past trauma, and one's fear of the effects of one's death on others (Yalom, 1980). Though palliative end-of-life education exists in some medical and nursing education programs, there is little research describing the effects of these programs when participants have or have not experienced a death of someone close to them. In a literature review by Verpoort, et al., (2004), non-oncology nurses (having less contact with terminally ill people) were concluded to be more in favour of euthanasia than oncology nurses. In one pre-test post-test study by Hurtig & Stewin (1990), 76 nursing students in Canada, (prior to any clinical experience) were recruited for a study of teaching approaches as part of a psychology course on adult development. They were randomly assigned to a death education program either using a didactic approach (i.e., lectures, films and group discussion), experiential approach (i.e., music, drawing, and death encounter exercises, such as guided life-death fantasy), or a control group (i.e., a simulation game dealing with independence in the aging adult and a lecture/discussion on adult development). Findings described a negative effect using an experiential approach on students with past familial death experiences in their willingness to confront thoughts concerning death, whereas those students without familial death experiences appeared to significantly benefit from experiential methods as compared to a didactic approach (Hurtig & Stewin, 1990). The finding is inconsistent with the results of a seminal pre-test post-test survey where experiential methods were successfully used with nurses (n=58) who were actively involved in care of terminally ill patients in helping them face their own death and demonstrating more open responses to dying patient statements (Ross, 1978). More recently, a study with 74 residents in internal medicine supports the argument that clinical experience is essential for self-perceived competence providing end-of-life care (Billings, Curtis, & Engelberg, 2009). To sum up, there is still inconclusive evidence about what kind of experience effectively draws clinicians closer to their own awareness of death and enhances their ability to talk about and/or help patients who are experiencing prognostic death awareness.
Oncology nurses often experience their greatest dilemmas during acute physiologic emergencies, however it is the suffering within the interactions and relationships with others that appears to provoke most of their distress (Cohen & Sarter, 1992). For example, disclosure of information is distressing when family members want nurses to collude and not inform patients of their diagnoses or prognoses (Dunne et al., 2005; Kendall, 2006a) or when patients, themselves state they do not want the information or wish to attend to existential issues (Milligan, 2004). In a study by Cohen and Sarter (1992), oncology nurses feared punishment for being "less than perfect" given their accountability to address suffering and help patients recover. They described experiencing the most work-related rewards as being when patients did recover, although some experienced benefit from being able to comfort distressed patients, and receive recognition from others for their care.

When cancer is a chronic illness, it is unclear when and at what pace to engage patients in existential care (Schofield, Carey, Love, Nehill, & Wein, 2006). Critical reflection of the emotive nature evoked in nurses’ work is suggested to expand opportunities for existential awareness with patients (Vachon, et al., 2010). In a randomized study of an intervention for palliative care nurses (n= 109), participants (n= 56) were asked to discuss the emotive nature and meaning in their work. While participants reported no change to their existential or emotional quality of life, they expressed benefit in coping with their end-of-life care (Fillion et al., 2009). In a descriptive survey by Duke and Appleton (2000), 160 scripts by registered nurses (i.e., pieces of reflective dialogue between themselves and their clinical supervisor) were marked for reflective skills. The nurses (n=62) were enrolled in an undergraduate post-registration palliative care course. Reflective markers included linking action with knowledge, that is, contextual, ethical, and professional action to personal and clinical knowledge. Despite that participants had considerable nursing experience and were employed in either palliative care, specialized oncology, or continuing care environments, the majority were more likely to describe practice
and less able to analyze knowledge as it related to their context of care and to an action plan. The authors concluded that some reflective skills associated with contextual considerations on care and action planning were difficult to achieve and might develop over time. However, until research informs how this development can be achieved and what facilitates or discourages it, authors suggested that reflective exercises might be seen as only an academic exercise, rather than a way of developing practice. Moreover, the study suggested that many nurses might not have felt in a position to make any changes in their practice as a result of constraints, such as a lack of resources or supports (Duke & Appleton, 2000). Thus, further research is needed in actual practice settings to explore the organization of care on nurses’ capacity for critical reflection, either on its own or in combination with other communication training strategies to engage nurses to talk about dying and death.

The Organization of Cancer Nurses’ Existential Care

Cancer nurses encounter challenges integrating existential care with curative treatment. “Medical action” versus "non-action" attempts to responsibly determine what is “best” for patients within perceived risks of treatment (Seymour, 2000). For nurses and physicians, a "technical" definition of death exists apart from "bodily" dying informed by practical experience (Seymour, 2000). Though a "technical" definition of death has been generated by medicine (Ellershaw & Ward, 2003), nurses often cope with the uncertainty of when and how patients’ deaths will be determined. In a study with intensive care staff, by foreshadowing experiences of what was anticipated to align trajectories of "technical" and "bodily" dying, nurses judged whether non-treatment was perceived as a causative link to patients' deaths. The negotiation of a nurse’s culpability for death of a patient constituted what it meant to "let die," versus "kill" and was especially difficult when transitions between curative and palliative end-of-life care were blurred and both approaches were not integrated (Seymour, 2000).
Historical attitudes and the organization of existential care within the Canadian health care system continue to create paradoxical interpretations of existential care within a palliative care philosophy and palliative cancer treatments, where an intent that addresses suffering of living with cancer is ambiguous. Some people assert that principles of a palliative care philosophy contradict palliative cancer treatments (de Haes & Koedoot, 2003; Kleffens et al., 2004). In particular, a palliative care philosophy provides treatment with the intent neither to hasten nor postpone death. In contrast, palliative cancer treatments, such as chemotherapy, radiation therapy, and surgery, previously given for curative reasons may be prescribed by physicians to preserve or prolong life. In doing so, some clinicians hope palliative cancer treatments may enhance quality of life and/or preserve hope of future longevity (Kleffens et al., 2004). The conflicting “palliative care” definitions indicate that cancer clinicians vary and may not necessarily be conscious of, or feel able to confront, or recognize when palliative care begins.

A study indicates that the question of when is the best time to introduce palliative care varies between professional groups of clinicians. Hospital nurses favour early referral while hospital doctors and general practitioners prefer later referral (Schofield, et al., 2006).

Many cancer nurses feel a need to attend to patients’ "total" pain experiences but often lack the knowledge of existential strategies and/or a palliative philosophy that supports an attitude to use them (Hollen, Hollen, & Stolte, 2000). Fear and misunderstanding of what palliative end-of-life means are linked to a reluctance in using these terms in curative cancer settings and to the uneven promotion of existential concerns. Information about palliative care services is left "discretely" by patients' bedsides or talked about in "hushed tones to those for whom nothing more can be done" (Ronaldson & Devery, 2001). As a result, there may be a tendency to misunderstand, ignore or avoid talking about existential issues because patients are not deemed palliative by clinicians, and thus explains why so many people requiring palliative
care interventions are felt to be referred late and patients' continuity of care is perceived as poorly compromised (Bestall et al., 2004).

Studies allude to the strong influence of the unit culture in influencing coordination and collaboration of existential care (Cohen & Sarter, 1992; Georges, Grynpoonck, deCasterle, 2002; Groot, Vernooij-Dassen, Crul, & Grol, 2005; Roman, 2001; Wilkinson, 1991). In a phenomenological study of outpatient cancer nurses (n=10) in the United Kingdom, technical administration of chemotherapy was experienced as interfering with the centrality of the nurse-patient relationship and dealing with patients’ suffering, death, and dying. Common sources of organizational stress in this cancer service were feelings of overload with work, poor management support, resource/ staffing limitations, lack of space/ privacy for patients and carers, and lack of teamwork (Mcilfatrick, Sullivan, & McKenna, 2006). Additionally, if the unit culture strived to demonstrate a scientific, task-oriented approach to efficiently manage ward millieu (Georges, et al., 2002; Sahlberg-Blom et al., 2001; Wilkinson, 1991), or did not have the resources of staffing, time, privacy, and mentorship of nurses (Cohen & Sarter, 1992), the nurses’ role to attend to issues in light of the threat of mortality was constrained. Thus, studies indicate that the culture and organization of work can influence compartmentalization of cancer nurses’ existential care. A few studies even conclude that attitudes to death itself, do not have a significant relationship to nurses caring for and about dying patients, but that the relational impediments of conflicting family expectations, lack of agreement among physicians, and unit or organizational culture restrictions may be more problematic issues (Beckstrand & Kirchhoff, 2005; Dunn, Otten, & Stephens, 2005).

The hospital culture focuses on goals and activities that prolong life (Middlewood, Gardner, & Gardner, 2001) in a context that often does not acknowledge the sense of "life-threatening" knowing. For example, one exploratory survey was used to assess the feasibility of using nurses' ratings of quality of dying to assess factors associated with quality end-of-life care
for patients in the highly technical environment of intensive care. Better quality of dying scores were associated with not having had cardiopulmonary resuscitation performed in the last eight hours of life, having someone present at the time of death, and having life support withdrawn consistent with a belief that this indicates family and clinicians have had an opportunity to prepare for the person's death (Hodde, Engelberg, Treece, Steinberg, & Curtis, 2004). Despite two of the three parameters being associated with relational processes of caring about the person and recognition of their nearing death, there was a lack of data about the processes of engaging in "talk" about knowledge of the threat of patients’ mortality or the patients’ existential suffering as a factor associated with the quality of dying.

Some clinicians recognize the mismatch of knowledge, pace, and resources between the health care system and patients' need to integrate concerns about mortality into their illness experiences, often not visible as anything more than referral to palliative care services (Ronaldson & Devery, 2001). The transition negotiated between a medical-technical definition of dying and a "natural" constitution (i.e., not caused by treatment) of dying (Seymour, 2000) is guided by nurses who may, and with much hesitation, be covertly promoting a palliative care philosophy underlying their work (Ronaldson & Devery, 2001).

The problem of how to integrate a palliative care philosophy is particularly apparent in bone marrow transplant settings where the transition from curative to palliative care can be sudden and unexpected. McGrath and Holewa (2007) conducted a descriptive phenomenological study with multi-professional health care staff and consumers of nine hospitals in three states in Australia. The aim was to develop a best practice model for end-of-life care in hematology. While data from interviews was collected from staff in nursing, medicine, allied health, consumers, leukemia foundation support workers, and hospice staff, the results of this study reported only on findings from the 19 acute care hematology nurse participants. Acute care hematology nurses expressed special considerations influencing how, when, and where end-of-
life care was offered to patients and their families. These factors were described as: high-tech invasive treatments, significant sequelae from treatment created issues about quality versus quantity of life, speed of change to dying (potentially fast), need for frequent blood tests and blood products, the possibility of catastrophic bleeds, varied diagnostic groups with different prognoses and disease patterns (i.e., acute to chronic), the fact that treatments can continue over many years, close patient relationships with hematology unit staff, clinical optimism based on a myriad of treatment options, unpredictability - occasionally patients showed positive signs of recovery even when close to death, and clinical indicators of the transition to the palliative stage. According to the researchers, the complexity of the 11 factors suggested an ethical imperative to balance the potential benefits against the harms of treatment in terms of quantity versus quality of life. Moreover, the study highlighted the problematic nature of ongoing curative treatment that blurred transitions to palliative care even while there were clear indications by nurses that patients approached the dying trajectory (McGrath & Holewa, 2007).

_Cancer Nurses Valuing Patients as Persons within Concerns of Mortality_

The moral nature of nursing care for people who experience existential suffering is evident in the literature (Davies & Oberle, 1990; Georges, et al., 2002; Maeve, 1998; Schwarz, 2004). In a nurse-patient relationship, valuing others is described as a global attitude of respect for the inherent worth of all humans as well as for the particular worth of the patient as a unique person. It is the inherent worth of all human beings that enables the nurse to persist in helping even under adverse circumstances (Davies & Oberle, 1990).

The ambivalence in incorporating a palliative care approach is often associated with the idea that "palliative" is equated with _imminent_ death, and despite nurses' intents to mitigate emotional suffering, clinicians are also attempting to respect the patients' autonomy (Balboni et al., 2007), which often means maintaining a distance that honours patients' dignity (Skott, 2003).
Paradoxically, when individuals are seriously ill and approaching death, the activity of nurses actually increases, as patients recognize the need to be dependent on nurses to take over tasks of bodily functions (Corner, 2002). Involvement by nurses needs to be "tempered" around balancing boundaries of intimacy and distance and "doing the right thing" (Aranda, 2001; deAraujo et al., 2004; Maeve, 1998). The challenge is coming to know what the proper response is and being able to do it through a combination of education, experience, and support from their work setting, where nurses learn to value patients as persons with unique wishes for approaching their death (Maeve, 1998).

The agency of nurses to attend to patients' prognostic awareness appears to be informed by their personal and professional values about what it means to be a person who is mortal. Some nurses value knowing how to 'be with' or 'being present' to "form a 'picture' of the man (person) over a lifetime and not merely capture the isolated stage of his (his/her) illness" (Dunniece & Slevin, 2002, p.15). In a study by Georges, Grypdonck, & deCasterle (2002), 10 palliative care hospital nurses in the Netherlands were observed over 35 days and described work that strived for different purposes; either a well-organized plan for discharge of the patient as soon as possible or ways to enhance the well-being of the patient. For those nurses that valued discharging patients efficiently, they adopted a professional rational attitude and avoided emotional stress. For those nurses that valued patients' experiences, they adopted a compassionate attitude that remained attentive and thoughtful to the distress of the patient and the nurses worked to cope with their own emotional strain (Georges, et al., 2002).

Oncology nurses need to value patients as individuals having the right to self-govern and be responsible for end-of-life decisions (Storch, 2004), which places ownership of life and death processes with patients themselves (Aranda, 2001). The literature describes nurses' roles as empowering, coaching, and advocating for patients as persons. Empowerment is described by an oncology nurse to involve facilitating and building on patient strengths, encouraging and
supporting patients' choices, defusing negative feelings, mending relationships to facilitate healing of family members, and giving information to help patients to comprehend treatment and make choices (Davies & Oberle, 1990). Responding to patient anger is described as a critical nursing behaviour in palliative care that requires empathy and a willingness to understand the meanings of a patient’s anger that might allow the patient to be accountable for his/her attitude to his/her illness (Degner et al., 1991). Additionally, the need to respond to families' need for information and negotiate appropriate choices is a role some nurses feel is essential to minimize the family's potential for future regret (Degner et al, 1991). As nurses are often responsible for negotiating conflicts in order to advocate for patients/families and secure everyday order and predictability (Schwartz, 2004; Volker, Kahn, & Penticuff, 2004), the commitment to care for people as persons, is extremely important. Further work is needed to reveal how nurses' reciprocally participate in enacting or perhaps inadvertently impeding patients' will and responsibility in the processes of adjusting to the existential threat of a cancer diagnosis, recurrence, or end of life care.

Arman and Rehnsfeldt (2003) suggest that some nurses may only be able to experience suffering as a struggle to be relieved or protected from, and therefore will not enter into discussions or interactions about the "darkness" wherein they may not have the answer, or for patients they wish to spare distress. Rather, they encourage nurses to merely create a safe place for suffering to occur that allows opportunities for patients to reintegrate and engage in transformation (even if it may not happen). Transformation is described in a literature review by Whitehead (2003) as an "expanded consciousness" created by an internal force (in different degrees within all individuals) that precipitates a positive health change. As part of attempts to ameliorate the experience of suffering, clinicians may offer opportunities to discuss existential beliefs or patients’ religious beliefs, or they may also simply ask questions such as, "How do you understand what is happening to you?" or "What would allow you to feel that going through this
has a purpose?" (Block, 2001, p. 2901). In responding to persistent requests for assistance in
dying, nurses were informed by a "moral line," that is, their intuitive judgment of a boundary
between "right" and "wrong," that was dynamic and dependent on knowledge of the patient's
context. Decisions were also informed by their existential or religious beliefs, previous
professional and personal experience, and fears of legal or professional sanctions (Schwarz,
2004).

The view that patients can grow within existential suffering is beginning to be recognized
in patients' experiences, however, nurses are generally not perceived as recognizing or actively
engaged in existential issues (Naden & Saeteren, 2006). While they may be willing to attend to
existential needs of patients, they have difficulty defining what such care ought to include
(Strang, Strang, & Ternestedt, 2002). Aranda (2001) pointed out that the refusal of nurses and
doctors to acknowledge the distress and smell of bodily decay may further isolate and silence the
patients' ability to speak about it. Additionally, reinforcing a refusal to acknowledge patients'
fears of dying and death may also prevent nurses from engaging in discussions that improve
nurses' practice. In Rasmussen, Sandman, and Norberg's (1997) study of 18 hospice nurses in
Sweden, nurses expressed feeling empowered and strengthened when they experienced closeness
and reciprocity from patients with who they were able to be with, and to share in the other's
suffering given the resource of time. In a recent phenomenological study by Hudacek (2007),
nurses’ stories of caring included a dimension of spirituality, however, this kind of care was
limited to ideas that they were guided in their work from a higher power, and not by other
dimensions associated with the threat of mortality.

In contrast to the previous study with hospice nurses, bone marrow transplant nurses
expressed much more difficulty coping with the personal impact of the almost daily reality of
death, revealed in some statements of "melancholy, a mourning disposition, and depressive
feelings" (deAraujo, et al., 2004, p.152). Despite these feelings, nurses expressed generally
liking their job, and cope through drawing strength from their existential or religious beliefs and ability to reflect to "recharge their batteries." When nurses were unable to achieve a sense of solace or solidarity with patients through empathy and care, they found it very difficult and/or frightening to relate to the patient. Consequently, their emotions contributed to an indifference and avoidance of dying patients (deAraujo et al., 2004).

To add to the complexity of work in bone marrow transplant settings, there is little recognition for how nurses make sense of their intense and intimate experiences with patients/families. In a study by Aranda (2001) with 12 nurses in a bone marrow transplant unit, nurses’ emotional involvement with patients’ suffering was judged by most nurses to be potentially harmful when it: contributed to potentially abusing the relationship to meet the nurse’s own needs; led to an inability to “recharge his/her batteries;” impacted on the distributive justice across all patients; or imposed on the nurse’s ability to make "objective" decisions. When a nurse did “cry out” to the team for help, the team tried to rescue her by preventing further continuation of the close relationship with the patient. The team's "silent condemnation of the nurse for her feelings towards a patient mimics the silence that surrounds intimacy in nursing" (Aranda, 2001, p.184). The author concluded that the greatest problem was having no supports for nurses who wished to reflect upon how human encounters affect them and their practice (Aranda, 2001).

What is generally lacking in health care research is an understanding of how nurses' professional development may be enhanced through appropriate emotional and motivational development of their embodied experiences with patients.

The Embodiment of Cancer Nurses’ Existential Care

Nurses can develop existential nursing practice through intuition, described by Newshan (1998), as an awareness of "one's inner source of truth and knowledge" that "arises from the spirit" and helps nurses "look beyond the physical aspects of pain and pain control, and bring in
existential resources or identify existential needs that are not directly expressed by the patient" (p.1240). Moments of "being with" and "being there" for patients are expressed as endorsing strong values of respect and the therapeutic use of self to demonstrate equality, trust, and commitment in coming to terms with a depth and unity of knowledge used in their care to help patients come to terms with death (Dunniece & Slevin, 2002). Embodiment of existential nursing practice is demonstrated in nurses’ physical and emotional feelings expressed in gestures and use of humour to bolster courage for dying patients (Maeve, 1998). During the research interviews conducted by Maeve (1998), embodiment was expressed in the ways nurses held their hands and arms to indicate a separation between themselves and some of their patients, and when some of the nurses placed their hand over their heart to emphasize their own sadness and pain (Maeve, 1998).

Palliative care nurses can learn how to simply "listen and be" with patients through recalling experiences where patients are at ease and achieve a sense of peace at death (Dunniece & Slevin, 2002). In a study of oncology nurses (Rittman, Paige, Rivera, Sutphin, & Godown, 1997) who had at least 5 years of work experience as well as personal experiences of death of a family member or friend, participants described narratives of dying patients involving four main themes: knowing the patient and stage of illness; preserving hope; easing the struggle; and providing for privacy (Rittman, Paige, Rivera, Sutphin, & Godown, 1997). Knowing the patient was dependent upon the nurse developing a close bond with the patient. However, if this did not occur, nurses relied on a familiar sense of knowing patients' needs and knowing how to enact care that led to patients' experiencing a good death (Rittman et al., 1997). In another study, muted changes and often non-verbal messages were reported to be the key to discovering a patient’s real wish to facilitate a peaceful death (Dunniece & Slevin, 2002). Thus, further insight into how nurses develop shared knowledge of the threat of patients’ mortality may support
nurses to understand what a personally ideal death is for individuals, and increase nurses’ confidence in being able to endure unavoidable suffering with their patients.

Hospice nurses “ought not to grieve when a patient dies,” but rather can be gratified by missing them and express being reminded of them, for example, when seeing a painting, being in his/her former room, or finding a personal item (Rasmussen et al., 1997, p.339). Contrary to this however, a palliative care nurse described a negative experience as a ‘turning-point’ to finding a ‘better way’ to practice (Dunniece & Slevin, 2002). Nurses’ expressions of emotional guilt, distress and regret about past experiences are suggested to enable breaking the silence that limits them from revealing their personal involvement with their patients (Maeve, 1998). In this way, nurses can grieve when nursing care "goes wrong" and can tolerate fears about perceiving patients as burdens or nuisances in order to contain their own vulnerability (Rasmussen, Sandman, & Norberg, 1997). In the qualitative study by Rasmussen et al., (1997), narratives of 19 hospice nurses revealed their search for making meaning of "undignified and a brutish suffering" that was difficult to tolerate. Some nurses, especially those that were inexperienced, did grieve and did not know how to contain and relieve the pressure in order to “save their energy.” This left those nurses feeling insufficient, helpless, and/or with flashbacks of those uneasy times. The literature suggests critical incidences are opportunities of failing to constitute a “good death” but make possible at the same moment, growth, in nursing practice (Rasmussen et al., 1997).

The tension of nursing care aspiring to achieve a “good” death versus a “bad” death for patients is probably most visible in narratives with patients in hospice settings. Care is described to be meaningful when patients are relieved of physical pain and discomfort, when patients die peacefully despite unavoidable suffering, and when loved ones and/or nurses are by their side (Rasmussen et al., 1997). In fact, "vitalizing" experiences, were described as "what ought to be" in narratives of patients whose death was considered tragic, but also was experienced by nurses
to be satisfying when patients’ dignity remained intact. This allowed families to endure the patients’ suffering (Rasmussen et al., 1997). In contrast, "devitalizing" nurses’ experiences were described as ones where they feel guilt, insecure, insufficient, and lacked a sense of endurance to patients’ suffering, particularly in scenarios involving time constraints or with patients' unexpected deaths. Some nurses expressed a sense of being cheated when patients died unexpectedly, as a result of having no opportunity to prepare for closure of relationships (Rasmussen et al., 1997). A sense of being fully present and attentive to the patient's suffering was experienced by some nurses as "draining their energy," and required leisure activities (e.g. exercise, humour) to replenish them (Rasmussen et al., 1997).

Some hospice nurses did not contain all the suffering and despair felt during their work, and therefore sought outlets to help them to reflect. Nurses used various strategies, such as maintaining diaries, talking to colleagues, and taking a sauna to symbolize "cleansing the mind" and creating space for their feelings (Rasmussen et al., 1997). When uncomfortable feelings persisted as a result of feeling unsure if they did the "right thing," resolution resulted only when confirmation by others occurred (i.e., colleague, family of patient, or patient's peaceful death), reassuring them that they "acted correctly" (Rasmussen et al., 1997).

When nurses experience distress, they may dissociate rather than integrate meanings that make sense of their work. Some described their work as "fighting a war against death that needs to balance 'being there,' with the need to perform multiple tasks of complex physical care, often during times of unexpected crisis" (Cohen & Sarter, 1992, p.1485). Many nurses described how critical incidents triggered reflections about their own experiences with illness or death of a loved one (Cohen & Sarter, 1992). Nurses often witness trauma that may evoke ethical and personal tension, particularly when they recognize their own vulnerability to the threat of mortality. However, rather than strengthening the meaning of their work, nurses in the previous study appeared to be continually drained by such experiences.
As human beings that share a sense of mortality, the literature suggests that nurses embody both positive and negative nurse-patient relationships. Thus, experiences of breakdown in their practice need to be supported by learning how to use these dilemmas to embolden them towards a pathway to improve their understanding of issues surrounding suffering and dying (Maeve, 1998; Rasmussen et al., 1997) as well as to incorporate these understandings into their own and others’ fears of dying (Rasmussen et al., 1997). To date, there exist only a few studies that suggest how intuitive knowledge of nurses is learned to inform either a sense of annihilation, separation, guilt and meaninglessness, or a preservation of their connection, reconciliation, and meaningfulness in their practice.

Qualitative studies suggest a clinician's own sensitivity to the threat of mortality plays a role in resilience and maintenance of well-being in palliative care, without which a nurse may find it difficult to address patients’ existential needs (Chung, Wong, & Chan, 2007; Ablett & Jones, 2007). A study by deAraujo, daSilva, and Francisco (2004) was one such study that accounted for nurses' emotional responses attempting to balance involvement that was "deeply moving," on the one hand, and "suffering" on the other. The capacity to reach a "balance" between the two appeared to depend on several factors, such as the degree of personal involvement, identification with patients and their family, nurses' personal psychological and emotional backgrounds, as well as the nurses' capacity to process and tolerate suffering (deAraujo et al., 2004).

A nurse’s capacity to process and tolerate suffering is a process that involves stress. The alleviation or augmentation of nurses' distress caused by cancer care is not well studied, however, the literature suggests as chronic stress, it can lead to emotional exhaustion, burnout, poor quality of care and even to large numbers of nurses considering leaving or decreasing their work hours (deCarvalho et al., 2005; Delvaux, Razavi, & Farvacques, 1988; Grunfeld et al.,
More than 30% of cancer care workers in Ontario are estimated to have high levels of emotional exhaustion and low levels of personal accomplishment (Grunfeld et al., 2000).

One of the most important variables is the process in which experience may bring intuitive knowledge of how to adequately respond to tacit and verbal cues with patients who face a heightened awareness of death (Degner & Gow, 1988; Dunn et al., 2005; Proctor, Grealish, Coates, & Sears, 2000; Roman, 2001; Quinn, 2003; Wright, 2001). However, a few exploratory surveys have shown that experience is not significantly associated with differences in attitudes towards dying patients (Rooda, Clements, & Jordan, 1999; Kuuppelomaki, 2003). In contrast, one study reported that more clinical experience lowered levels of difficulty in communication and personal issues, not due to the number of terminally ill patients the nurse has worked with, but due to personal and professional maturity developed over time (Sasahara et al., 2005).

Indeed, the greater awareness nurses had about end-of-life issues, the more difficulties they reported as a result of problems encountered in dealing with the "ideal" versus "actual" care provided (Sasahara et al., 2005). As an example of this dilemma, in a qualitative study of oncology nurses, those with more experience had more positive attitudes about advance directives but felt they did not have enough time to discuss them with patients (Jezewski et al., 2005).

Experiences that hinder the provision of existential care are probably most apparent in settings where “actual” care does not meet expectations of what is considered “ideal.” Despite findings that bone marrow transplant nurses express personal growth and accomplishment from their work, they may still report symptoms of emotional exhaustion (Molassiotis & Haberman, 1996). In a large bone marrow transplant centre in the United States, a sample of 40 nurses were asked to complete a series of standardized scales for the purpose of: (a) assessing emotional difficulties in a group of BMT nurses who have access to an informal staff support program, (b) highlighting differences and/or similarities compared to BMT nurses who participated in similar
research and had no access to staff support services, and (c) drawing tentative conclusions and/or suggestions that may help staff overcome emotional difficulties. Twenty one (52.5%) of nurses reported symptoms of moderate emotional exhaustion or reported low emotional exhaustion. High emotional exhaustion was reported by four nurses (10%). The same subjects who were highly emotionally exhausted had also a high degree of depersonalization, while 37.5% (n=9) reported moderate depersonalization. Seven (17.5%) and nine (22.5%) nurses reported moderate and low personal accomplishment, respectively, from their job. Burnout is the combination of all these symptoms, that is, high emotional exhaustion, high depersonalization and low personal accomplishment. These results were consistent with patterns of low burnout syndrome among the study subjects, accounting for 9 to 10% of the present sample. However, the researchers suggested that the moderate cases of burnout (accounting for up to 52.5% of the nurses) needed special attention before they developed all signs of burnout syndrome. Furthermore, one of the main problems identified among nursing staff was the high incidence of anxiety, experienced by one out of four nurses. This number became higher if the borderline ratings of anxiety were also included. While the psychosocial staff support program, although informal, offered nurses a variety of services to manage possible sources of work-related stress, it was not tested directly, and as such, it was unclear whether and to what extent the program contributed to improving nursing morale. Moreover, the nursing staff's low level of psychological stress may have been a residual outcome of a formal "model" staff support program that previously existed in the same hospital where the study took place. Finally, it was of importance to note that the more years of experience with BMT patients was associated with a lower incidence of burnout (Molassiotis & Haberman, 1996). Though the previous study was 14 years old, results still resonate in current literature extrapolated from the greater group of cancer nurses’ experiences who feel frustrated with their supportive care.
Discussion

The literature indicates that cancer nurses experience difficulties engaging in existential care, particularly in acute care settings. On the one hand, nurses are philosophically open to disclosure with patients about their illness concerns, but they also attempt to conceal or suppress negative emotions or avoid emotionally sensitive areas. While a simultaneous or integrated approach using both curative and palliative approaches are theorized to aid clinicians to shift gradually from curative to palliative intents (Schofield, et al, 2006), there is a lack of in-depth knowledge about the tension in these competing and coinciding kinds of care. To date, most knowledge about existential care is located in the context of palliative end-of-life care and not in acute care contexts.

The gaps are especially apparent where patients experience near-death crises and sometimes die on acute care units, such as in bone marrow transplant units. Many of these services lack resources to support palliative intents and to integrate approaches conducive to transitions to palliative end-of-life care. Unfortunately, little empirical literature exists about how clinicians experience and respond to concerns about patients’/families’ existential distress, particularly if technological and curative aims seem to conflict with this kind of care.

The provision of existential care is not well articulated in the cancer nursing literature, especially as it applies to developing expert care during shared and intimate moments with patients’ existential distress. Additionally, the limitations from the review indicate that there is little understanding as to how cancer nurses tolerate fears of their own mortality or whether their fears can be alleviated to enhance their resilience and retention. Given that society continues to avoid death and prolong life, the concern that cancer nurses will withdraw from these distressing experiences may be justified, but is scarcely addressed by the studies in this review.
Summary

This review suggests that cancer nurses potentially have considerable impact on patients' journeys throughout the cancer trajectory in dealing with life-threatening illnesses and in finding meaning of their suffering. This is particularly relevant in cancer nursing practice that values the centrality of knowing the patient and engaging in existential care. If the patient is at the centre of care, then cancer nurses are compelled to tailor their interventions to what patients need, or find resources to support them. However, the results from this review do not answer how cancer nurses do this when aims of curative care can suddenly change to palliative intents in the context of aggressive life-saving treatment, as in bone marrow transplant units. To date, the literature does not reveal cancer nurses’ situated knowledge of contextual influences or their emotional involvement with the fluctuating awareness of the threat of patients’ mortality and growing recognition of patients’ dying and death.
CHAPTER IV: PHILOSOPHICAL AND THEORETICAL UNDERPINNINGS OF
SITUATING SELF TO ENTER INTO CANCER NURSES’ EXPERIENCES
OF THE THREAT OF PATIENT’S MORTALITY

There is an element of death in life, and I am astonished that one pretends to ignore it:
death, whose unpitying presence we experience in each turn of fortune we survive
because we must learn how to die slowly.
We must learn to die: all of life is in that.

(Selected letters of Rainer Maria Rilke who suffered from leukemia and died at age 51 in the
year 1926.)
The purpose of this chapter is to articulate the philosophical and theoretical underpinnings of this study. In particular, I discuss how I entered into studying my research questions using the hermeneutic circle. The hermeneutic circle is a process of questioning that critically reflects on preconceptions, biases, and past experiences of the research phenomenon. From this point of view, my interpretation was made possible and evolved from there. Last, I discuss how the central tenets of Benner’s (1994) interpretive phenomenology prepared me to reveal new phenomenological understanding of cancer nurses’ existential care.

Situating Self Using the Hermeneutic Circle

According to Benner (1994), interpretive researchers need to create a dialogue that critically reflects on the ways “that any one set of prescribed methodological strategies, personal knowledge, and social context creates theoretical and perceptual access influencing understanding” (p. 99). Benner’s use of the hermeneutic circle appears implicit and embedded in the process of entering into interpretive phenomenology and doing analysis; hence appears hidden. As a novice qualitative researcher, I attempt to be transparent about how I understand and used the hermeneutic circle in this study. I draw from what hermeneutic philosophy calls the “forestructure” of understanding, associated with my research phenomenon.

The “forestructure” of understanding consists of shared public understanding based on: i) fore-having, a practical familiarity of practices that makes interpretation possible, ii) fore-sight, a point of view from which to make an interpretation, and iii) fore-conception, expectations of what is anticipated in an interpretation (Plager, 1994). To allow the participants’ voices to be heard and understood, researchers needs to lay out their preconceptions, biases, past experiences, and theoretical relationships that makes the project significant to them and which forestructures understanding for themselves and the study participants (Plager, 1994). Entering this “circle of understanding,” or ontological circle, commonly referred to as, the hermeneutic circle, means the
researcher acknowledges his/her preunderstandings, but respects the possibilities of the phenomenon showing itself in new ways (Benner, 1996).

Fore-having: My Taken-for-Granted Background

According to Benner (1994), the researcher "can never escape his or her own taken-for-granted background or stance that creates the possibility of an interpretive foreground" (p.100). Hence, it is impossible to neutralize background understandings, especially as it is these very understandings that have led to the interest in studying the substantive topic and the way in which the study is approached (Lopez & Willis, 2004). My world is constituted as a Chinese-Canadian woman, connected to others as a wife, and mother of two sons. Furthermore my personal experiences of being with dying family members (described in part in the prologue) has led me to situate myself in the topic of existential concerns. Additionally, my professional experiences have contributed to my understanding of nursing. As a general medical nurse, I worked with patients with serious illnesses (6 months experience). As a mental health nurse, I worked with the impact of psychological distress and disease and the importance of interpersonal processes in nursing care (14 years experience). These experiences situated my sense of *fore-having* practical familiarity of nursing and the health care context. They also offered me a stance in which to make an interpretation. To note, I had never worked as a nurse on a cancer service, and therefore, remained open to seeing and hearing possibilities of what was salient in this context.

Fore-Sight: The Origins of my Philosophical and Theoretical Underpinnings

The philosophical and theoretical underpinnings are based on central tenets of *interpretive phenomenology*, as articulated by Patricia Benner (1994; 1996; 1999; 2001). Benner is a nurse and professor at the University of California, who derived a research methodology
founded on a *Heideggerian phenomenological perspective*. Much of her research has been in similar settings of cancer and intensive care, both of which are dominated by ideas of life-saving technology. Her concepts primarily come from two philosophers, Heidegger and Merleau-Ponty. According to Benner (1994), background assumptions that constitute our knowing in the everyday world can not be based on an epistemology that answers what it is to know. Rather, Benner (1994) asks, “*Why and how we ‘know’ some things and not others and what constitutes our knowing*” (p.102). Hence, I returned to my research question and asked, how and what constituted my ‘*knowing*’ in relation to nursing existential care.

Given meanings can be rationally interpreted; the use of informal models of causation in interpretive phenomenology can be a resource that can frame, focus and orient the inquiry. As a consequence, evidence needs to be provided that the presuppositions and use of a framework do not unreasonably bias the realities of given participants' narratives, though they are acknowledged to influence the interpretation (Benner, 1994). I acknowledge that in addition to Benner, I sought a conceptual understanding of the threat of patients’ mortality to direct me to “see” the phenomena in nurses’ narratives.

Yalom (1980)’s work with cancer patients is also based on *Heideggerian phenomenology*. Yalom (1980) is a physician, psychotherapist, and professor of psychiatry in Stanford University. His ideas come from his work and research with cancer patients, their experiences of life-threatening illnesses, and the existential impact on them. He provided me an approach to understanding cancer patients’ experiences based on existential phenomenology.

Yalom’s ideas coincide with philosophical underpinnings of Benner. Both Benner and Yalom drew from existential phenomenology to understand sources of commonality in experiences of individuals. Together, Yalom’s (1980) and Benner’s (1989; 1994; 1996) philosophical and theoretical underpinnings offered me a way to explore how nursing practice engages specifically with the threat of patients’ mortality. Furthermore, *Benner’s (1994; 1996)*...
interpretive phenomenology as a methodology, honors an ontology and epistemology that seeks to uncover common meanings situated in relationships. As a methodology, interpretive phenomenology was best suited to my research question to allow for commentary (my own and the participants) that directly explored a phenomenon irreducible to variables of cause and effect and measurement using standardized instruments.

The goal of interpretive phenomenology is to “understand world, self, and other” (Benner, 1994, p. 99) by moving back and forth between foreground and background, between situations, and between practical worlds of the participants” (Benner, 1994, p. 100). The way in which Benner does this is by uncovering commonalities (and differences) from sources situated in relationships. These sources consist of: a) background meanings reappraising what it means to be a person based on a mechanical model, b) embodied knowing that encompasses skillful comportment, perceptual, and emotional responses experienced and expressed by the body, c) situated contexts (i.e., contextuality) of how persons historically and currently take up possibilities based on linguistic and cultural understandings, and d) concerns of how people are oriented meaningfully in situations to notice what is salient based on what matters and is temporally projected as concerns in their future (Benner, 1994); the latter source theoretically supports the development of expertise in nursing practice through a process called the skill of involvement. The skill of involvement is defined as practical know-how that “sees” possibilities based on past experiences projected to be meaningful in future situations (Benner, 1996).

Interpretive sources from which to explore commonalities, formerly described by Benner (1994), guided my fore-sight or point of view. Hence, I was guided by four themes as they related to nurses experiences of the threat of patients’ mortality: 1) background meaning of the threat of mortality, 2) the cancer patient embodied in concerns of existence, 3) the contextuality of health care and the threat of patients’ mortality, and 4) the skill of involvement in cancer nursing existential care.
Background Meaning of the Threat of Mortality

A philosophical approach is required to uncover ways to facilitate a "proper" death. North American culture tends to define a "proper" death as an event in our future, which we can exercise control over. Modern technology reflects this way of being and thinking, and applies it to everything as an overarching dominant reality (Heidegger, 1993). Unquestionably, modern technology demands a way of being that is implicitly shared and public. Benner and Wrubel (1989) call this background meaning. Background meaning allows things to matter and be understood in a particular way. Historically, this knowledge was thought to be rooted in a causal mechanistic model of what it means to be a person. The cognitive nature of that knowledge was organized into abstract or generalized categories of how people belonged and what they did (Benner, 1989). In this way, we could exercise control over people and things. Even our deaths became something we could control, postpone, and/or make ourselves ready for, if not for ourselves, for others, with bodily donations of fluids and organs. In this way, according to Heidegger (1993), technology brings forth "facts" about things, but in this way, says nothing about the relationships that guide intentions and expectations of its end. In this way of being, humanity is merely a collection of technological beings and we exist in an accessible way; a way where we can make everything transparent, that is, evident, and readily known and understood.

While the mechanistic model of what it means to be a person has fallen out of favour to explain our emotions, goals, and purposes (Benner & Wrubel, 1989), aspects of it, such as mortality rates, remain in our search to know and control death’s occurrence. Nonetheless, the threat of mortality is not an occurrence or event. The threat of mortality involves an inherent existential fear that one may face a future beyond death to nothingness. Once we live beside death, the indefiniteness may go with it because one's being does not wish to live alongside death, but with death "ahead-of-itsel," that is, within a basic constitution of there being something "still left to be settled," prior to our end of life, according to Heidegger (1962, p.279).
Technology reinforces the idea that we can live alongside death by knowing its essential nature and controlling death's occurrence. This leads to a tendency to minimize any value in recognizing and attending to suffering that occurs to us as we live alongside an awareness of our mortality and possible death.

The knowledge of our boundary or limit is not instrumental to us. The threat impels us to continually ask, "What more can be done (or settled) before death?" Furthermore, the anxiety pervading death stems from the possibility that there may be no future of a conscious existence after death (Heidegger, 1993). In other words, revealing a time of death challenges our conscious awareness to consider what it means to have a will to live when a future of a conscious existence is uncertain.

The closer we are to the idea that we can die at any moment reminds us that we all share a human connection constituted by a "boundary" or "limit" situation of death. Death is the limit situation that we all share and need to transcend or overcome in some way. "Death is the condition that makes it possible for us to live life in an authentic fashion" (Yalom, 1998, p.31). If however, we attempt to outstrip death either because we recognize we can not defend ourselves from death and/or do not know how to be responsible for it; we live in a forgetfulness of being (Heidegger) and are only aware of our becoming. "Life shrinks when death is denied" (Yalom, 1998, p. 187). In other words, death is not simply a fact of life or the last moment of life but its lifelong consideration can enrich life with an immediate sense of meaning (Yalom, 1998). "Although the physicality of death destroys man, the idea of death saves him" (Yalom, 1998, p.30). When the threat of mortality is considered in present everyday moments, what shows up as mattering is how people are involved in situations through their concerns, skills, and practical activity (Benner, 1989, p. 407).

Health care discourse is only beginning to struggle with how to bridge the limit or boundaries between acute care and palliative end-of-life care. Perhaps the experiences of
repressing, accepting, and transcending suffering constitutes *temporal fluctuations* in an awareness of the threat of mortality. *Temporality* "does not refer to the linear passage of time, but to the way the person is anchored in the present that is made meaningful by past experiences and by the person's anticipated future" (Benner, 1989, p.412-413). To date, there is not a shared common understanding of how temporal concerns of patients and nurses inform what a "proper" and "improper" idea of death is for individuals. Without this knowledge, the work that affects existential care can not be passed on in ways others can learn and incorporate knowledge into their everyday practice.

*The Cancer Patient Embodied in Concerns of Existence*

What shows up as mattering is what concerns us. *Concerns are* the way people are oriented meaningfully in the situation (Benner, 1994). Concerns of existence matter in several countries (i.e., Canadians, Americans, British, Chinese, Japanese, Jewish, Australians, and Swedish) as reported in chapter two. Past concerns of the *way* things were, are taken up in *being-in-the-world*, that is, in present ways of being projected into the future. *Being-in-the-world* is a Heideggerian term that is concerned with involvement *that selves live their dying* in matters of the present moment (Yalom, 1980).

Dying is understood intellectually, but according to Yalom (1980), is rarely acknowledged in our way of being involved in the world. According to Heidegger (1962), we enter into embodiment of a “technological” world. As technological beings, our bodies are oriented to an unconscious way of being called forth to generate systematic actions based on reasoned and analytical decisions. However, working through knowledge, inquiry, and relationships in practice can *not* be oversimplified to tasks or lists of possible actions and classifications. According to Benner, Hooper-Kyriakidis, and Stannard (1999), “good” practice requires aesthetic and ethical understanding.
Aesthetic understanding refers to knowledge that is taken-for-granted in relationships with patients and families and socially negotiated as clinical situations unfold. Ethical understanding involves our sense of risk and authentic responsibility in relationships with others. Being involved in our world will naturally show up what matters (i.e., "fore-sight") in lived experiences, as well as what is anticipated to matter in being faced with dying (i.e., "fore-conception") (Heidegger, 1962). Knowledge of concerns are embodied in the logics of nursing work. In this study, they are assumed to be implicit in focused observations of nurses’ work and in nursing narratives that embodies what “the threat of mortality is.” Analysis of what matters and why it came to be that way will get at the underlying taken-for-granted understandings of nurses’ experiences.

Yalom (1980) considers the threat of mortality to be a fear of the future related to the contingency of life and its fragility. According to Yalom, his research and practice with cancer patients reported four ultimate matters of existence: 1) fear of death; 2) isolation; 3) (anxiety and responsibility concerning one’s) freedom; and 4) meaninglessness. A diagnosis of cancer is a "confrontation with death” because it brings one nearer to death and brings to the forefront an awareness of death anxiety synonymous to an unexpected "fear of death, mortal terror, or fear of finitude" (Yalom, 1980, p.42). Primal sources of anxiety are conventionally defended against so that Yalom asserts that clinicians rarely encounter death anxiety expressed in a conscious way. All fears related to death are those triggered by an urgency of a future towards the event of dying, ceasing to be, and what comes after death (Yalom, 1980).

Existential isolation is a universal phenomenon referring to "an unbridgeable gulf between oneself and any other being...an isolation—fundamental to a separation between the individual and the world"(Yalom, 1980, p.355). Yalom considers facing death to inevitably lead everyone into a sense of darkness— of a basic separateness— whereupon there is a sense of helplessness and the world is suddenly unfamiliar. The familiar everyday world of routine
activities and their meanings hides our primordial isolation until we experience something jarring
and previous meanings attached to objects and symbols are lost. A person's capacity to connect
with patients who suffer unconscious existential isolation depends to some extent on their
capacity to value others as sentient beings, like themselves (Yalom, 1980).

*Freedom* is strangely an experience that is not traditionally perceived as a worry in
Western culture valuing choice and autonomy. The notion of freedom is used in the context of
being *situated* to create his/her own life—constituted to be the author of his/her destiny—to
desire, to choose, and to act. The world is constituted by meanings around a perceived
responsibility to build an identity with freedoms. Responsibility is an existential concern because
it means possessing authority to constitute being "there" and to constitute "what is" there. The
nature of being is to build an external structure to constitute "self, destiny, life predicament,
feelings, and if such be the case, one's own suffering" (Yalom, 1980, p.218). However, to
experience one’s responsibility of their existence in this manner is “deeply frightening…The
very ground beneath one seems to open up,” (p. 221). Indeed, the term “groundlessness” is used
for the subjective experience of *responsibility awareness*.

Both Benner (1989) and Yalom (1980) suggest that one’s freedom exists only to the
extent that it reveals certain possibilities that show up against the background of their situation or
social network. With the diagnosis of a life-threatening illness, such as cancer, there is a loss of
previous freedoms in patients’ situations, and therefore, the loss of will to command their
situations. However, a heightened awareness of the threat of mortality may also enhance an
individual's agency and perceived responsibility to pursue living their dying in a way that is
authentic and meaningful to them. Hence, one’s freedom is connected to an individual's capacity
to see possibilities of agency and feel responsible to project his/her constitution of a future
(Yalom, 1980).
Lastly, *meaninglessness* refers to a loss of coherence in life's purpose. This is a sense of having nothing to struggle or hope for. On the other hand, a search for meaning is the search for a "personal" and/or "cosmic" patterns in the world. Personal meaning is constructed towards a purpose based on living while fully engaged, perhaps towards goals of self-expression (e.g. dignity) or self-transcendent goals (e.g. altruism). Cosmic meaning is defined as "some design existing outside of and superior to the person and invariably refers to some magical or spiritual ordering of the universe" (Yalom, 1980, p.423).

The threat of patients’ mortality is contemplated to raise affective and relationally felt responsibility in nurses and other health care providers whom patients are dependent upon for their agency. Patients' and nurses' boundaries become blurred in the process of negotiating a shared agency of mind (nurse as advocate) and body (nurse as instrument to whether and how patients are free to act). The impact on the patient is evident given his/her vulnerable position in the relationship, but what of the nurse? It is unknown if and how nurses acknowledge and engage with patients' experiences in light of their threat of mortality and what felt responsibilities this triggers for nurses.

*The Contextuality of Health care and the Threat of Patients’ Mortality*

For this research, people who face a threat of mortality and dying are within structural and social practices of a health care system, specifically an acute care hospital. Hospital institutions struggle with philosophical ideals of "cure" and "care." This is reflected in the literature reviews of this dissertation that reveal divergent dialogue between health care providers and patients, whose descriptions of their lives and aspirations differ in light of their awareness of the threat of mortality.

Benner (1989) uses the words “background meaning” to refer to what allows for the perception of the factual world or what “counts as real for the person” (p.407). The hospital
context shares background meanings or public understandings of what it means to cure cancer. Health care providers share agency with patients to maintain being "in control," to be peaceful, and to have bodily boundaries maintained and private. The constructs of "hope" and "life" for health care providers primarily appear to mean "to survive" in ways that the patient's body is a machine (Benner & Wrubel, 1989).

In contrast, while there are shared concerns given to "life" and "living," patients appear to be living differently, embodied in a displaced world where they are unfamiliar with the hospital's historical, cultural, and social routines. These experiences isolate patients from a former sense of feeling “at home” or dwelling in their bodies. Patients, even early on in their cancer diagnoses, express vulnerability to being at war with one’s own body that alters their bearing (Benner & Wrubel, 1989). Patients embody fears of an unknown enemy inside of them, alienating themselves from a former sense of self. Furthermore, this alteration creates experiences of shame and humiliation as a result of a loss of bodily integrity and exposure of intimate parts of their bodies in hospitals (Benner & Wrubel, 1989). A health care provider may be desensitized to feelings and images of patients’ worlds, or they may simply not have a sense of self that dwells on the fragility or finiteness of life.

There is a lack of knowledge and empathic understanding about how health care providers' interpret patients'/families' understandings, which compete with the background meanings of hospitals. The need to engage in this kind of skilled involvement is imperative in order to systematically build on clinicians' skills and skilled practices. Nurses require more conscious discussion of communication skills that talk about the threat of mortality and dying. According to Benner, Tanner, and Chesla (1996), nurses need to understand qualitative distinctions of how clinical care may be built to philosophically and pragmatically share common purposes that honour patients' wishes and meanings given that they dwell in a world facing a compelling threat of mortality and face possibilities of dying.
The rhythm of health care practices within the hospital context is out of sync with the individual's bodily rhythm to gradually incorporate into the self, a life-threatening diagnosis as it relates to one’s awareness of mortality (Benner & Wrubel, 1989). A dynamic and social process particular to being skillfully involved with terminally ill individuals asks that cancer nurses explore patients’ fears associated with an uncertain future. The embodiment of cancer nurses' practical knowledge is assumed to be occurring and evolving through local understandings of being with patients as persons who tolerate a fluctuating awareness of their mortality and approaching death.

The skill of involvement consists of practical know-how and sensitive ethical judgment acquired by experiences of learning to be actively involved in situations that allow intuitively grasping "correct" perceptions of the whole situation and not its precepts (Benner, 1984). Practical know-how is defined by Benner (1984) as "clinical know-how" that is different than theoretical formulations of "knowing that." It is knowledge embedded in clinical experience revealed when "preconceived notions and expectations are challenged, refined, or disconfirmed by the actual situation" (Benner, 1984, p.3). Tanner, Benner, Chesla, and Gordon (1996) have described the dynamic process of practical knowledge through analyzing nurses' narratives of what it means to know the patient and how differences of knowing the patient shape nursing care. In order to develop know-how, nurses need to reflect on the patient’s pattern of responses to treatment, as well as the immediate demands and concerns of each situation (Benner et al., 1996).

Nurses describe knowing the patient as central to the meaning of their work: "getting a grasp of the patient, getting situated, and understanding the patient's situation in context with salient nuances, and qualitative distinctions" (p.207). Having a good grasp of the particular patient means having "in-depth knowledge of the patient's patterns of responses and knowing the
patient as a person” (p.208). This knowledge is expressed in the nurse’s responses to knowledge of the patient's therapeutic measures, routines and habits, coping resources, physical capacities and endurance, and body topology and characteristics (Benner, et al., 1996).

The knowledge of particular patient populations, their common issues, expectations, and preferences becomes defined and refined in the development of particularized knowledge that becomes part of the nurses’ background (i.e., embodied). At any one moment, new possibilities stand out (that is, matter) based on how it compares and connects with past knowledge that informs and shapes projections of the future. Collecting instances and contrasts over time create ethical comportment to temporal truths (Benner, et al., 1996).

Temporality, interpreted by Benner (1994), is constitutive to being in time; existing as directional and relational to having had a "being-ness" and "being-expectant” (Heidegger) of a particular future” (p.105). One projects his/herself into the future as understood by his/her past. “Temporality is not experienced in the abstract” (1989, p. 67). Temporal truths are specific and formed by what is shared and anticipated through common understandings of language and practices with others (Benner, 1989). By revealing salient aspects of temporality in the hospital context with particular patient populations, clinical know-how and ethical judgment for nurses can been illuminated in ways that reveal how nurses attempt to negotiate, regulate, and/or resist contexts that govern their social concerns, i.e., the patients and their own. According to Benner et al., (1996), moving from novice to expert requires proficiency in which nurses read relevant aspects of a situation and respond in a socially skilled manner. This manner requires “global understanding based on the integration of past experiences” (p. 116).

Outside of basic nursing education, formal structures for fostering the skill of involvement are almost nonexistent (Benner, Tanner, Chesla, 1996). Interpersonal skills in caring for dying patients are learned primarily through experiences that refine, elaborate, and disconfirm previous (fore)knowledge and stand out as a reference point for predicting and
projecting future clinical practice based on meaningful patterns. Strong concerns or ways of becoming "involved" in clinical episodes "stand out" as moments shaping future practical knowledge (i.e., "skilled know how"). "Expert" nurses no longer rely on rules, or guidelines, but after an "enormous background of experience" (Benner, 1984, p.32) are intuitively grasping situations holistically. Nurses’ knowledge of the patient expresses intents of valuing involvement, and having an attachment to patients.

Perceptual acuity is transformed through a process of envisioning possibilities and acting ethically in the context of changing situations. The nurses’ involvement enables them to particularize formal prescriptions and abstractions through understanding how this patient responds under these circumstances. Learning how to be skillfully involved with vulnerable people is an everyday aspect of practice, which is presumed to evolve through engaging in many different social and personal situations with patients in hospitals (Benner, et al., 1996). In the process of being emotionally attuned to their patients, the nurses can accurately perceive what this patient’s distress means and respond in the appropriate way (Benner, et al., 1996). Nurses, as the primary caregivers at the bedside, are concerned and frequently advocate ethical actions held collectively with others to bring about the inherent notions of what is “best” for patients/families (Benner, et al., 1996).

As nurses develop expertise, they navigate everyday practice as a socially-mediated ethical process that is largely taken-for-granted in the ways the body takes over practical “know-how,” known as the skill of involvement (Benner, et al., 1996). The ways in which this study attempts to capture a mismatch of intentions, expectations, meanings, and outcomes is through revealing aspects of relationally, dialogically, and contextually embedded knowledge commonly created by fluctuating tensions of what nurses sense is “best” for the patient/family and what actually occurs at any one moment in their situations.
Fore-Conception: My Interpretation of the Lived Experiences of Cancer Nurses

A central tenet of interpretive phenomenology assumes that all understanding takes place in naturally occurring narratives that reveal mutually constructed understandings of what matters to people. As such, Benner (1994; 1996) assumes that how interactions are situated reveal either unreflective practical knowledge or ways people have learned what is salient through experience. The conversational stories engage individuals (teller and hearer) in dialogical reasoning of familiar shared background meanings for consensual validation and/or competing conversation (Benner, 1994).

According to Benner (1989), the relational nature of nursing care is situated within all the ways people are connected in the world, revealed in action based on taken-for-granted understanding of background meanings and concerns. These sources of commonalities are embodied and constitute our similar cultures, which give us access to familiar dialogue and practical understanding (Benner, 1994). While individual interviews were the primary source of data in this study, this method was supplemented with observations where nursing activities took place. Observations allow the researcher to reveal possible conflicts, contradictions, or surprises given tacit backgrounds that are taken-for-granted to the participants (Benner, 1994).

According to the literature reviews, research is only beginning to reveal shared meanings that inform contrasting perceptions between the patients' and the clinicians' lived experiences of the threat of mortality and the pervasiveness of death. Interpretive phenomenology assumes these differences originate from a way of being engaged within different worlds and backgrounds. Thus, the research approach seeks to understand meanings within assumptions of locally competing life worlds that differ, but are bounded by common meanings that matter in historical, temporal, and cultural practice.

The experience of how the threat of mortality unfolds in a clinical episode of care can not be reduced to abstract or general constructions about that experience. However, everyone is
predisposed through interactions with others (i.e., orientation, gestures, posture, stance) to search for an understanding of their experiences, including experiences of suffering. Any one person's understanding, is therefore, self-defining in a primordial way of being embodied (i.e., internalized styles, habits, and expectations) to face death in ways that constitute and sustain meaning and purpose in one's life (Yalom, 1980). However, nurses are assumed to be searching for shared commonalities with others that "fuse" the nurses' and the patients' "horizons" together in order for meaningful communication to take place (Benner, 1994). The research approach used in this study adheres to a stance that can reveal commonly held explicit and implicit values of how nurses conceptualize their agency to give integrity and meaning to their work shared with patients/families (Benner, 1991). The context, content, and function of nursing interactions are illuminated to reveal a complexity of nuances that help grasp engaged reasoning of meanings (Benner, 1984).

Interpretive phenomenological research attempts to grasp concerns given that only a limited number of (one or two "best") possibilities can account for the shared everyday worlds of a practical situation that is "bounded" by the timing, language, and intentions of the participants interpreted by the researcher (Benner, 1984). Unlike a tradition of ethnography that assumes the researcher can make explicit cultural patterns that may be implicitly hidden to the participants (Chambers, 2000), interpretive phenomenology has been chosen in order to illuminate dialogical truths in the active creation of narratives that limit content and meanings to what can be accessed through active listening and empowering participants to tell their story in their own words (Benner, 1994).

Benner's methodology has been successfully used in studies of nurses (Benner, 1984; Benner, Hooper-Kyriakidis, & Stannard, 1999; Tarlier, Johnson, & White, 2003) to capture discourse of practical reasoning that reveals understanding that might have gotten covered over by everyday familiarity (Benner, 1994). Note that Benner's methodology is modified for this
study, not to include strict ideas of *years of experience* to define nurses as “novice” or “expert” in cancer nursing existential care. This does not resonate with current literature questioning whether experience directly leads to expertise of existential care. Rather, the focus is to use methods that reveal practical reasoning of "what is perceived, what is worth noticing, and what concerned the storyteller," (Benner, 1994, p.110). This practical reasoning informs knowledge and thick descriptions of salient issues and judgments towards cancer nurses’ expertise to bridge gaps between theory and practice (Benner, 1994).

Summary

In attempts to be transparent about how I entered into studying cancer nurses’ experience of the threat of patients’ mortality, I explicated how I situated my self using the hermeneutic circle. My understanding of the hermeneutic circle was intuitive in that I was *already thrown* into a taken-for-granted historical, social, and cultural background. This background motivated me to study the research phenomenon and to question my *fore-having* (preconceptions, biases, past experiences) of understanding. I also brought *fore-sight* or a point a view based on my familiarity with nursing and the health care context. Additionally, I considered four phenomenological sources guided by Benner (1994; 1996) and Yalom (1980) from which to explore shared and public meanings of the research phenomenon: 1) background meaning of the threat of mortality, 2) the cancer patient embodied in concerns of existence, 3) the contextuality of health care and the threat of patients’ mortality, and 4) the skill of involvement in cancer nursing existential care. Benner's (1984, 1994; 1996; 2001) interpretive phenomenology structured my *fore-conception* of my research, aligned to uncover practical concerns (i.e., ways of being involved through intentions and expectations with people) that inform and judge the adequacy of formal theories. According to Benner et al (1999), this reveals the embedded logic of practice that is different than logic of science or one to discover theoretically correct explanations about the practice (as
in grounded theory methodology). Rather, interpretive phenomenology goes beyond description about the phenomenon to find common meanings and concerns that establish patterns of relationships shared in particular situations (Benner, 1994). This kind of practical knowledge is embedded in the "immediate" clinical practice of nurses and describes the combined historical (experiential) and theoretical knowledge that can only be judged within understanding the "wholeness" of particular situations (Benner, 1984). The focus and thus, my research questions were aligned to Benner's perspective to explore special events, practices, or things that gathered special significance for nurses. These activities constituted their capacity to be proficient with their application of knowledge informing their skilled involvement with patients and their families over time.
CHAPTER V:

RESEARCH METHODS
In this chapter the study purpose and research questions are reiterated, and research methods described. A description of the recruitment process includes gaining access to the setting and sampling procedures. Demographics of the study participants are provided followed by strategies of data collection, and how data was comprehended, synthesized, theorized, and re-contextualized to ensure criteria of rigour. Lastly, considerations of ethical conduct in the study are discussed.

Research Questions

The purpose of this study was to explore nurses’ experiences of being with cancer patients facing the threat of mortality on bone marrow transplant units of one institution in Canada. The specific research questions were:

1. How do nurses experience the threat of patients’ mortality?
2. How do nurses engage with the threat of patients’ mortality?
3. How does the context of inpatient bone marrow transplant units situate nurses’ work within concerns of the threat of mortality?
4. How do nurses cope with caring for patients who face the threat of mortality?

Research Setting Description

During April to October 2007, the study took place in a large acute care hospital devoted to cancer research, education, and clinical care in the downtown core of a large multicultural city. The hospital has an “international reputation as global leaders in the fight against cancer.” Here, “caring relationships with patients are valued,” and there is a “commitment to combine state-of-the art diagnosis and treatment with compassion and care” (Institutional setting website, 2010). The hospital houses one of the largest bone marrow transplant (BMT) programs in North America.
The BMT program consists of autologous (donor and recipient are the same) and allogeneic (matched donor, either genetically related or unrelated to recipient) bone marrow transplant units as part of the Haematology/Blood Disorders Services. All inpatient services are supported by a nurse manager, clinical educators, and advance practice nurses. Both the autologous (auto) and allogeneic (allo) bone marrow transplant (BMT) units have a rich supply of staff, including doctors, a full-time pharmacist on weekdays, and a ward clerk. Additionally, a large variety of health care professionals are regularly involved on both units: physiotherapists, a wound care nurse, resident doctors, a chaplain once a week, social workers, infection control staff, blood technicians, occupational therapists, dieticians, and staff from a partnering hospital’s intensive care unit (ICU) who transfer patients to their unit.

Nurses in the BMT setting work in a highly technical environment and deliver care using a primary nursing approach with an interdisciplinary team. Nursing activities are described on the hospital’s website as "managing ongoing medical treatment, vigilant monitoring for emerging hematological crises, and responding to emergency situations." Nurses use a variety of complex nursing skills including physical assessment, administering chemotherapy, and blood products, and the provision of psychological and emotional support to patients and their families. As an integral part of the team, nurses collaborate directly with physicians in determining the treatment plans for multiple symptom management and emergent needs. Nurses are expected to have excellent verbal and written communication skills for practical work including de-escalation of situations in which patients and their families are in crises. Effective communication skills with patients and their families are expected to involve the development of close relationships that facilitated supportive care and teaching. The strong research based environment provides opportunities for nurses to empower themselves with learning activities. Continuing education and self-directed learning are supported by the health care organization.
Gaining Access to the Setting

The setting included two bone marrow transplant inpatient units of one organization, one autologous unit and one allogeneic unit. A member of my thesis committee and the nurse manager negotiated my entry during discussions about enhancing nursing research concerned with issues associated with patient-focused care. I established contact with the nurse manager who expressed support for the study. A discussion with the nurse manager led to choosing both allogeneic and autologous units to increase diversity of nurse-patient relationships within a homogenous setting. The same nurse manager provided guidance for nurses in the selected hematology oncology BMT services, and staffing on the units was similar, that is, five nurses on the 12-hour day shifts and four nurses on the 12-hour night shifts. More specifically, the staff to patient ratios were one nurse to three patients (personal communication from Nurse Manager, March 31, 2006). Both the study setting’s BMT units were located in the same hospital, each with a bed capacity of 14 to 15 patients, and directed by similar processes within interdisciplinary teams.

Research ethics boards in the academic and hospital institutions provided ethical review of the study (Appendix A and B). Contact was made with the nurse manager to arrange the process of providing information to the units through their hospital intranet and nursing team meetings. Information sessions were conducted about the study during nursing team meetings on each unit during both shifts (days and nights). For future reference and to generate interest or answer questions about the study, I posted information providing a brief overview of the study in flyers (Appendix C) in staff conference rooms for nurses and allied health care professionals.

Differences Between Allogeneic and Autologous Units

While the two units were similar in spatial structure and nursing routines, allo bone marrow transplantation carried a greater statistical risk of death. A nurse, named Zhanna,
conceded that this was due to the greater potential for treatment-related complications in transplants from unrelated donors (i.e., allo).

Auto transplants…don’t have as high a mortality rate because of the side effects…whereas, all the allo transplants, they’ll come back to our floor, if they're sick, most of the time…it's mainly ‘cause of treatment-related mortality. So if you have an unrelated transplant you’re…where graft versus host is a lot higher, rejection, all that sort of stuff… Whereas, if you have a related transplant…the genes are somewhat similar to yours, so risk of graft versus host is not as high. So you're less likely to die from all those side effects. (Zhanna, allo unit)

Due to the potential complications of treatment when recovering from allo BMTs, patients remained in the allo unit an average of 4 weeks; whereas patients undergoing auto BMTs remained in the auto unit an average of 2 weeks.

Sample Selection

Inclusion and Exclusion Criteria

A convenience sample of front-line Registered Nurses (RNs) was purposively selected from two of the four inpatient hematology oncology bone marrow transplant inpatient services, whom the nurse manager felt were receptive to a nursing study. Participants who were eligible for the study included all full-time and part-time RNs who were in direct care of patients. On the two BMT units, a complement of 50 full-time and 25 part-time oncology nurses worked in direct patient care. However, they were eligible only if they provided voluntary written consent. Voluntary consent included a commitment to one or two interviews arranged at a time and place of participants’ preference. Participants also had to agree to the researcher observing their practice for two to three hours in public areas of the unit.

Casual RNs and those on orientation were excluded due to the potential that their work differed from full-time and part-time RNs, due to the sporadic nature of their involvement with patients and their brief experience on the units.
Sample Size Determinants

Similar to Benner's own dissertation (as cited by Benner, 1994), an anticipated sample size of at least 20 participants of varying work experience was thought to be enough to reach a redundancy of patterns, though the exact number remained open to account for the quality of text generated and the way the line of inquiry developed over time (Benner, 1994). Nineteen of 20 RNs voluntarily agreed to participate, but one dropped out due to lack of time for the interview. The final sample size was determined only after members of the research committee agreed that data saturation had occurred. At that time, recruitment ceased and the final sample size was 19 RNs.

Recruitment Strategies

Recruitment strategies were used to minimize any sense of coercion to participate in this study. The ward clerks on each unit forwarded an email message to all eligible nurses on the BMT units through the hospital’s intra-net system. The email provided nurses with a brief synopsis of the study and invited them to contact the researcher for more information. Following the e-mail message (Appendix B), I discussed the study at team meetings during both shifts on each unit to answer any questions or concerns about the purpose and about the benefits and risks to participants. During that time, information flyers with an explanation of the study for nurses (Appendix C) and allied health care workers (Appendix D) were given at the end of the discussion, and left in the staff lounges and nursing stations. When nurses contacted the researcher, I invited more questions and comments about the study. If they remained interested and agreed to participate, I took his/her contact information and provided him/her the option to meet with a research associate, not directly part of the study, to obtain informed written consent (Appendix E). In all cases, the participants had the option of 72 hours to consider their participation before consent was obtained. I explained to participants that they could decline
participation with no explanation or negative consequences. If contact was not made with the participant after two weeks, or the participant did not contact the research assistant, then participation was assumed to have been declined and no further contact was made to recruit the participant.

Only one nurse contacted me in response to the initial e-mail distribution recruitment message requesting more information and an interest in participating. Many more nurses expressed an interest and verbally agreed to participate in the study following the information sessions held on the unit. Once I began field observations on the units with a participant nurse, my presence generated further interest and questions associated with the study. In this way, I developed rapport with the nurses and facilitated recruitment of the final group of participants.

Nurses voluntarily participated and were found to have a large amount of variation in the number of years of nursing experience, types of nursing education, the kinds of death experiences with significant family, and how they spoke about their religious affiliations. As well, a few participants were identified by nurses to be good informants because they were seen as experts in establishing rapport with “difficult” patients and in communication that supported transitions from the acute to end-of-life phase. Initially, I intended to have at least 10 RNs purposively recruited from each 12 hour shift (i.e., 0700-1900hrs; 1900-0700hrs) because shifts were purported to represent variations of culture in the same work setting, and each shift was seen to potentially influence attitudinal differences towards terminally ill people (Roman, 2001). As it turned out, most nurses were found to work both days and night shifts, and therefore, this variation became irrelevant. After approximately six months of recruitment, and data collection concurrent with analysis, I reached saturation of preliminary themes and ceased recruitment of participants.
Determining Data Saturation

Data collection occurred concurrently with data analysis. Analysis was done with two investigators independently, and then together, for the first four interviews and every third or fourth interview thereafter. While no participant was interviewed a second time, theoretical patterns were clarified in subsequent interviews as data collection progressed. Redundancy of patterns was determined to occur after the sixteenth participant. However, I continued on with three more interviews until the nineteenth participant, to verify that the addition of more participants did not add any new information about the phenomenon. In consultation with my supervisor and one other investigator in my thesis committee, we agreed that the repetitive nature of my data conformed to ideas of saturation (Speziale & Carpenter, 2007). Hence, saturation occurred with the nineteenth interview and after six months, data collection ended.

Data Collection and Recording

Data collection involved four sources: 1) demographics of participants, 2) focused observations, 3) individual interviews, and 4) field notes within 24 hours after the focused observations and individual interviews.

Demographics of Participants

At the start of the interviews, participants were asked to provide demographic data (Appendix G). Empirical literature strongly indicates personal moderating factors influence how nurses approach existential issues with patients. As such, age, sex, education, years of nursing experience (Degner & Gow, 1988), spiritual or religious affiliation (Schwartz, 2004; Wilkinson, 1991; deAraujo, daSilva,& Francisco, 2004), and experiences of death of significant family
(Hopkinson & Hallett, 2002; Hurtig & Stewin, 1990), were collected from participants to supplement data analysis.

Nineteen RNs participated in the study, 18 females and one male. Nine (9) were from the allogeneic BMT unit, nine (9) from the autologous BMT unit, and one that floated between both the allogeneic and autologous units. Fourteen (14) of the RNs had full-time status and five (5) had part-time status.

When asked if he/she had experienced a death of a loved one (family or friend), 17 participants responded “yes,” and two responded “no.” Fourteen (14) stated he/she had a spiritual or religious affiliation, while five (5) stated that he/she had none. The study participants reported that 6 had a college nursing diploma, 11 had obtained their Bachelor of Science in Nursing, and 2 had their Masters of Nursing. All participants acquired an oncology nursing certificate from the Canadian Nurses Association as a requirement of working on the BMT unit. Three had taken a workshop or seminar in palliative end-of-life care. Demographic characteristics of nurses’ ages, BMT unit experience, and cancer nursing experience are summarized in table 1 below.

Table 1.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Range</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>24 – 64 yrs. old</td>
<td>42 yrs. (SD= 12)</td>
</tr>
<tr>
<td>BMT Unit experience</td>
<td>1 – 25 yrs.</td>
<td>7. 4 yrs. (SD= 6.0)</td>
</tr>
<tr>
<td>Cancer experience</td>
<td>2 – 33 yrs.</td>
<td>11.6 yrs. (SD= 8.5)</td>
</tr>
</tbody>
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*Focused Observations*

Prior to an interview, observation time was arranged with each participant based on the participant’s work schedule. I reintroduced myself to the ward clerk and charge nurse, answered any of their questions, and began my field observations only after obtaining reconfirmation of the participant’s consent. During each observation, patient census on the unit was noted, as was
the participating nurse’s patient assignment. The participating nurse often informally discussed her schedule and plans for the upcoming shift with me. Focused observations occurred only in public areas of the unit, during which notes about the artifacts, the physical space, routines, and social and cultural nature of the context were recorded in a research journal. Occasionally, other nurses asked me questions about the study or recommended a nurse colleague whom I might approach to participate due to his/her expert communication skills. All interactions were noted in a research journal. At the end of the focused observation, a coffee coupon was given to the participant as an acknowledgment for his/her participation.

A tool guiding data collection during focused observations facilitated writing field notes (Appendix F). Descriptive questions guiding observation followed a framework by Clandinin and Connelly (2000): interaction, continuity or temporality, and situation or place. I recorded data in different ways during my observations. In the initial observations of each unit, I focused first on observations about the situation or place, that is, the physical structure and artifacts on the unit, but also paid attention to where exchanges occurred and what occasions and types of discussions took place with colleagues. As the observations continued, I became more focused on activities that shaped care, that is, the personal and social interactions of who and how interactions were initiated, the tone of exchanges, and the group dynamics. Lastly, I focused on observing the ways communication occurred on the unit and a sense of their collective understandings about work involving the threat of patients’ mortality.

Through my observations, I was able to access how nurses shared understanding of their expertise with each other (and with me). They offered each other multiple perspectives about patients’ needs, in moments involving coaching or support. In some instances, I observed nurses and health care providers formally passing on patient information or informally talking about each other’s lives. Observations assisted in understanding how nurses’ work was clinically and ethically interdependent on the agency of others. I noted that during a few informal interactions
(breaks), nurses talked about notions of what was “good” for patients in the context of the threat of patients’ mortality. When assent to listen was given by the group, I listened intently but remained silent so as not to influence the conversations.

My ethical commitment to remain in public areas of the unit prevented me from directly observing care of the participating nurses with patients. This constraint led me to discover that after three field observation events, I did not generate any new data after two to three hours of focused participant observation. Therefore, I chose to limit future observations to approximately two hours per participant. The total time observed on both units was approximately 40 hours, given to observations on day and night shifts, weekdays and weekends. NOTE: I did not directly observe patients due to ethical considerations given to the vulnerability of them and their families. I also did not influence or participate in any direct care associated with patients on the units.

**Individual Interviews**

Though Benner (1994) advocated the use of small group interviews with nurses, I decided that the sensitivity of the topic was not advantageous to providing time for participants to enter into what mattered in their stories. Additionally, I considered participants vulnerable to being judged by others, who might consider their practice in light of controversy about their intimate connections to the patients, they cared for and about. As a result, I decided to conduct individual interviews with each participant in a quiet place of his/her preference, and at a time that was convenient. Interviews ranged from 40 minutes to 90 minutes, an average of 60 minutes each. All but two participants requested that the interview take place on their BMT unit, in one of the staff rooms used for their breaks. Furnishings of staff rooms were similar on each unit and located off one of the hallways near the patients’ rooms. Staff rooms in which the interviews took place were quiet with no windows, consisting of two couches, a phone, and a microwave.
The other two interviews took place off the participant’s BMT unit: one in a private room located off the unit in the hospital, and the other in the privacy of her home. All participants received an honorarium of $50.00 each for their time providing an interview.

Interview Script

A brief interview script (Appendix H) guided participants to provide patient narratives, particularly as it applied to comparing observations and meanings of: a) how nurses experienced work in caring for people on the hematology oncology unit, and more specifically what it was like to care for people who faced an uncertain future and perhaps, dying; b) what were the working conditions of the unit and what activities were (or were not) engaged in light of the serious nature of their illness or patients dying; and c) what they wished could have been done differently and how they coped with their feelings or thoughts after these experiences with patients. I used my judgment and discretion as an experienced mental health nurse to give participants the opportunity to interrupt, slow down, or stop the interview as required.

My supervisor and I initially piloted the interview script with three oncology nurses at a different but similar work setting to ensure clarity of the questions and to practically test and refine data collection techniques. This pilot resulted in some minor modifications of interview prompts. I used prompts to explicate, confirm, and clarify salient intentions, meanings, and expectations of nursing care. More specifically, questions prompted more detail of nurses’ narratives and to further enhance participants’ memories to recall the events that occurred. Articulating detailed aspects of the patient situation was particularly important to understanding whether the events were ordinary/typical or were particularly demanding and why (Benner, 1984).

Transcription of Individual Interviews

Participants provided permission to tape-record all interviews on a digital voice recorder. Once in a while after the formal interviews were concluded, participants continued informal
discussions with me that were relevant to the study. During those times, I asked for permission to re-start the digital voice recorder to include the data in my study, and/or hand wrote the conversations in as much detail, and as soon after as possible.

A professional transcriber was employed to transcribe all the digital voice recordings according to given prescribed standards of transcription (Appendix I). The transcriber was oriented to the sensitive and potentially traumatic nature of the data to ensure that they were prepared and could receive support in such cases as they wished to talk about the data to me and maintain its confidentiality. Transcriptions of the interviews eliminated names, characteristics, and any individual ways or expressions that identified participants. Interviews alone yielded more than 60 sample units, given that at least three episodes of care were elicited from each participant. As the primary source of data, interviews generated 531 pages of transcripts.

Field Notes

Within 24 hours after the individual interviews and focused observations, I typed up field notes and make reflexive memos to more fully capture the impressions and emotions of the researcher and participants. Each observation was considered a distinct sample unit or episode of care. Consistent with Spradley (1979), to make deeper and more general sense of what is happening, there was a combination of field notes using a set of notation characters to separate different types of entries: short notes made at the time; expanded notes made as soon as possible after each field session; a fieldwork reflexive journal to record problems and ideas that arose during each stage of fieldwork; and a provisional running record of analysis and interpretation. I recorded field notes following predetermined guidelines (Appendix J).

The analytic log or audit trail was a provisional running record of general impressions of the data and the unfolding investigation, ideas about meanings encountered in review of transcripts, emerging interpretations of the fieldwork, and insights into differences in
participants' circumstances, problem engagement, emotional involvement, and their reasoned action. Field notes complemented questions guiding observations of participants. The field notes also served as a record of ideas generated during interviews, supervisory and advisory team meetings.

Data Management

Data from field observations and interviews were entered into a computer software program, called NVivo7 from QSR International. The use of computer software was used as a tool to facilitate searching, linking, organizing data to parts of the text (as “naming” represented chunks of data), representing and storing reflections, ideas, and theorizing. The computer software was not used to do the analysis but to aid in enhancing rigour within consistency in reviewing data, speeding up time spent on a thorough use of search and retrieval strategies, creating graphic maps of relationships to visualize and extend thinking about the data, and to consolidate all data from interviews, field notes, reflective memos, and demographic variables (Weitzman, 2000). The software called NVivo7 supported highly structured coding systems and enabled building an interactive matrix to attach corresponding text to display cells of data represented by "naming" salient parts of the text, meaningful patterns, and finally, themes (Weitzman, 2000) that continually evolved in a process that reframed the data through several reiterations. NVivo7 allowed each and every part of the texts to be marked for their links to each other for subsequent retrieval.

Data Analysis

Interpretive phenomenology, according to Benner (1984, 1994, 1996) requires multiple readings of texts to analyze parts within whole narratives that remain "close enough to the text to preserve the temporality and contextuality of the situations" ... but which also have "an ability to
move back and forth” continually between what is familiar across situations, what is interpreted to apply to a specific situation, and what is anticipated to be interpreted in other situations (i.e., the hermeneutic circle; [Benner, 1994, p.77]). While I brought philosophical and theoretical understandings of what I would interpret to be salient to the topic of patients’ existential distress, I took a stance to ensure I heard and understood the participants’ voice by trying to put these preconceptions aside. As such, the analytic process was iterative and began as more of a descriptive, rather than explanatory account to understand, interpret, and critique the text using thematic analysis. As analysis continued, the conscious use of the hermeneutic circle facilitated moving into a more explanatory account of why it came to be that way.

**Analytic Strategies**

According to Benner (1984), knowledge is embedded in clinical nursing practice. To get at the knowledge, researchers engage in a rigorous and systematic process of first sorting data and then using two analytic strategies to move back-and-forth between the whole text and its parts. The two analytic strategies were thematic analysis and the hermeneutic circle, guided by Benner’s (1994; 1996; 1999) interpretive methodology.

**Thematic Analysis**

I systematically developed and defined descriptive names during initial readings of the texts to get a sense of the “whole.” The process of establishing “names” occurred with several in-depth readings of the text both as a whole and in its parts. As possible common meanings emerged, so did new lines of inquiry that uncovered discrepancies and inconsistencies. Thematic analysis generally followed these steps:
a) Naming to capture examples of “meaning in action,” based on the context (e.g. “fostering the fighting spirit”). Naming text also created a basis for comparison to other parts of text, for similarities and differences across them.

b) Mapping a descriptive account using common meanings, personal (or nurses’ prior) knowledge, and unplanned delegation of responsibilities or practices. Common meanings are "taken-for-granted background knowledge that is not socially negotiated in an explicit way" (Benner, 1984, p.292). Background knowledge becomes apparent in narrative accounts of diverse clinical situations because intentions and meanings remained implicitly understood and intact for purposes of understanding in communication. Narrative accounts were examined for assumptions and expectations, indicating implicit understanding and intentions of participants’ actions.

Personal knowledge is the prior knowledge that creates experiences. Each individual brings preconceptions and prior understanding to transactions with others that reveal his/her particular history, intellectual commitments, and readiness to learn in a clinical situation (Benner, 1984).

In this analytic process, two types of text stood out: i) strong examples of nursing care as being "new or puzzling aspects...recognized as important but largely unarticulated" (Benner, 1996, p.362). An example of this was “the nurse as the come-to person”; And ii) strong examples identified by nurses as important "because they changed or reoriented the nurses' practice" (Benner, 1996, p.362). An example of this was “knowledge of patients’ patterns of dying.” By grouping names in this descriptive way, analytic decisions revealed similarities and differences, and clarified distinctions of patterns based on assumptions and expectations (e.g. “bursting the bubble of hope”).

The initial thematic account was mapped out visually for constant comparison of named parts of text and common meanings to the whole texts for broad understandings of complex
meanings (e.g. “ambivalence to bursting the bubble of hope”). Thematic analysis linked several names amongst multiple parts of the texts to form descriptive clusters of meaningful patterns of action. Analytic decisions were discussed to clarify distinctions and similarities amongst meaningful patterns, stances, and situated concerns of participants. Several iterations of the mapping of the text (“naming”) and patterns of meaning (sub-themes) occurred over time, allowing access to patterns of inquiry as well as to direct new lines of inquiry in the process (Benner, 1996).

The Hermeneutic Circle

As data were collected, they were systematically analyzed for "naturally occurring questions and dialogue within the text, and to articulate the understandings created by the process of reading (and re-reading) the text" (Taylor, 1991, 1992; as cited by Benner, 1994, p. 114). As salient aspects of text were named and analyzed, they were then explored as a whole story and back again in their parts to allow judgment of salient concerns and meanings (names) to be refined for "best" fit to patterns of meaning (Benner, 1994).

Interpretations informed researchers’ understanding of nurses’ taken-for-granted background (fore-having), ways that developed or altered it (fore-sight), and ways that clinical "know-how" and ethical judgment were deemed to be important to future situations (fore-conception). Having identified, compared, and contrasted salient aspects of situations, meaningful patterns, stances, or concerns were clarified for distinctions and similarities (Benner, 1994). Portions of the text (named) and portions of the analysis informed perspectives of the whole story and allowed the researchers to go back and forth between parts and wholes to confront and develop themes for an explanatory account of the data (Benner, 1994).

Dialogue in the hermeneutic circle continued in a stance of involvement to the situational and temporal context of participants. Competing perspectives and counter-stories, such as
“fighting cancer while preparing for the possibility of letting go” were not used to negate each other or set up false dichotomies, but to encourage critical analysis for practical learning. For example, in the aforementioned conflicting perspectives, the situated contexts of participants were explored for how they reflected different concerns of culture, language, and individual situations. While my preconceptions of the context of acute care and the embodied threat of patients’ mortality held divergent dialogue, a process of questioning occurred when I realized nurse participants did not necessarily experience valuing one intent over the other, but held onto both almost until patients died. This initial misunderstanding reflected my own taken-for-granted background that led to questioning attitudes that altered my preconceptions interpreting nurses’ experiences.

Analytic Process

My supervisor and committee assisted the process of analysis. The first four interviews were inter-dependently analyzed and every fourth one thereafter with the supervisor for plausibility of claims. The dissertation committee conducted an analysis of preliminary results after the data were collected, to further challenge, alter, and open up the researcher to new interpretations and lines of inquiry. Additionally, the nurse manager arranged for study participants and other “interested” nurses from both of the participating units to provide comments about the descriptive or theoretical validity of the preliminary results. This helped to further ensure credibility and plausibility, discussed under the section: “criteria of rigor.” Verbal permission was given by all the respondents to incorporate their comments as a whole (not as individuals) into the final analysis as "new" additional data. Although descriptive validity was not challenged by participants, conceptual definitions around what participants deemed “palliative care” were re-considered as primarily supportive care that held palliative intents but
were not palliative. This knowledge was incorporated into the incisiveness of interpretations, while not compromising the credibility of the researchers’ interpretations.

Meanings given to the actions described in the text shifted to explanations of why it came to be that way. An explanatory account was based on a level of commentary that clarified meanings and intents in previous levels of description (e.g. “letting go” did not mean “letting die” but letting go of norms of control in the curative culture). Drawing from my philosophical and theoretical underpinnings, an interpretive commentary was built on the main theme and four sub-themes that captured meanings and qualitative distinctions of nurses’ experiences. “The goal of the interpretive commentary is neither a total systems account nor a single-factor theory. Interpretive commentaries or theories are not considered more ‘real’ or ‘true’ than the text itself” (Benner, 1994, p.101). As such, the purpose was to develop an interpretive commentary that did not reduce meanings or intents to a model of power or exchange, or role negotiation. Rather, the final interpretive commentary sought to be a commentary of how nurses engaged in reasoning through conflicting concerns of their situated existential work.

Criteria of Rigor

Rigor was ensured within strategies that adhered to three central tenets of qualitative research: credibility, plausibility, and transferability.

Credibility

Credibility is defined as the extent to which the study resonated with the lived experience of those being researched (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). "Does the research, as reported, illuminate the subjective meaning, actions, and context of those being researched?" (Popay, Rogers, & Williams, 1998,p.345). Strategies to establish credibility were: 1) prolonged engagement in the field allowing continual refinement of the emerging analysis; and 2) continual negotiation to perform member checking that allowed for a commitment to
faithful re-interpretations that participants would immediately recognize as "ringing true" to their own experiences (Sandelowski, cited by Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998).

A form of respondent validation was completed with a group of ten nurses approximately six months after data collection was completed. Five nurses from each of the study units participated, including three of the ten study participants who were available to attend the meeting. The purpose of the respondent validation was to more clearly frame and clarify the findings from perspectives of similar nurses on the participating BMT units. Only participants’ pseudonyms were used in these preliminary findings and case descriptions of patients/families were disguised to protect the anonymity of those patients that nurses, as a group, might recognize. The questions I asked were: Do these findings resonate with your experiences of work on the BMT unit? If so, how so, or if not, how might I consider the findings differently? Overall, the responses were acknowledged to “ring true” for representatives; however, respondents were adamant that care on the BMT unit should not be perceived as “palliative.” While they acknowledged that patients were often critically ill and did sometimes die on their units, meanings given to the word “palliative” were contrary to meanings provided by life-saving treatment.

Credibility was further enhanced with: 1) sampling sufficiency (i.e., participants who best represent knowledge of the topic) based on a dynamic relationship between data collection and thinking theoretically to expand or reasonably change direction of analysis (Morse, Barrett, Mayan, Olson, & Spiers, 2002); and 2) methodological coherence, which is the congruence between the research question, especially how and why it changed over the course of the research, and the methods for data collection and analysis (Morse, et al., 2002). The research question "as a positioning device orients readers to the kinds of knowledge that were sought,...informs their appreciation of the interpretive stance taken to the data, and constitutes a
point of reference for comprehending the substantive analysis put forward” (Eakin & Mykhalovskiy, 2003, p.191). Methodological coherence was demonstrated by clearly conceptualizing and analyzing data consistent with central tenets of Benner’s interpretive phenomenology.

**Plausibility**

Plausibility is the accountability to make claims based on comprehensiveness (quality of data) and sufficiency of descriptive data selected and presented (Popay, Rogers, & Williams, 1998). In other words, claims rendering names, patterns, and themes are assessed as reasonably concluded (i.e., no leaps in interpretation). The reader can interpret intentions and meanings that follow nurses’ experiences as a process, provided there is a rich description of participants' context (Popay, et al., 1998). Strategies to ensure plausibility included use of research triangulation through the combination of multiple data sources (i.e., artifacts, observations, interviews), empirical strands of literature, and multiple investigator perspectives (including supervisor and advisory committee members) to consider different facets used in an analysis (Popay, et al., 1998). Investigators with knowledge about research methodology and the substantive area provided consensus for research interpretations, which enhanced confidence of investigator responsiveness (Benner, 1994). Additionally, I enhanced plausibility for interpretations using strategies that facilitated reflexivity and investigator’s responsiveness.

**Reflexivity** is the researcher's ability to be sensitive to the ways his/her presence in the research setting contributed to the data collection and how presuppositions shaped the data analysis (Murphy, et al., 1998). Reflexivity is an ongoing self-critique and self-appraisal of the positioning of oneself to the substantive topic and how this shapes the knowledge generated (Koch & Harrington, 1998). The question was not whether the data were biased, but "to what extent had the researcher rendered transparent the processes by which data were collected,
analyzed, and presented" (Popay, Rogers, & Williams, 1998, p. 348). The extent the interpretations demonstrated that I was thoughtful and consciously self-aware was important. Note that as a research tool, reflexivity was not self indulgent but a way to open up possibilities to hearing the other’s voice.

Findings from the focused observations were brought into the interviews to clarify and deepen understanding of nursing routines and meanings given to artifacts. As the data collection process and analysis revealed salient patterns, I used subsequent interviews to affirm and clarify similar or differing views of the experiences previous participants brought forth, while at the same time trying not to lead participants to similar conclusions. Questions of other participants (without names) were posed in a neutral manner, such as, “Other participants have told me…, what you think about that?” I did not request a second interview of any of the participants, though all agreed to provide one if necessary. Movement or transitions from my presumptions was considered an important component of the analytic process and recorded in field notes to enhance the quality of interpretations (Benner, 1994).

My reactions to the interviews with participants were kept in a fieldwork journal. The journal held a continuing and dynamic self-awareness of my experiences and thought processes during data collection. In doing so, the journal served as a progressive account of my emerging understandings of the phenomenon. I discussed these reflections with my supervisor and advisory committee to help crystallize analytic ideas.

The investigator's responsiveness is evidence of creativity, sensitivity, flexibility, and skill to relinquish ideas poorly supported and to work towards social inquiry that inductively "inches forward without making cognitive leaps, constantly checking and rechecking, and building a solid foundation" (Morse, et al., 2002, p.13). Strategies that demonstrated reflexivity and investigator's responsiveness occurred through writing field note conventions of condensed and expanded accounts as soon as possible following interviews and observations, and writing in
an analytic and interpretive journal. The journal contained an audit trail to examine the process by which I arrived at different facets of the reality. Analysis drew upon the audit trail of reflexive memos and the fieldwork journaling to emphasize the inter-subjectivity of interpretations (Murphy, et al., 1998).

Change in One Research Question

As a result of my field notes, there was a significant shift in one of my research questions. Originally, I asked a question: “How do nurses’ skills engaged in the threat of patients’ mortality develop through their personal and work experiences?” However, by the end of the fourth interview, data clearly revealed that nurses were unable to articulate how their existential skills and attitudes were understood, integrated, or developed in their work. Though participants expressed awareness that they did not learn skills through their formal education, they were unable to explicitly articulate what, whether, or how their skills were developed. Furthermore, this question did not address a salient concern brought up by participants, but myself. Hence, I discovered that what mattered to participant RNs was how they coped with the tensions that the threat of patients’ mortality in their work. Hence, I relinquished the former research question and pursued the latter one.

After confirmation from my supervisor and one other member of the advisory committee, the last question of my research study was changed to align with participants’ concern: “How do nurses cope with caring for patients who face the threat of mortality?” Following the lead of participants is important to interpretive phenomenology as the focus is to use methods to reveal "what is perceived, what is worth noticing, and what concerned the storyteller," (Benner, 1994, p.110). Interpretive phenomenology situates analysis in a context, and provides the reader with thick description, so that the researcher's responsiveness coherently and transparently reveals how behaviours were viewed from within a culture, society, or group (Popay, Rogers, & Williams, 1998). Given variability of the phenomena was inherent, confirmability, which is the
ability to account for instability in the research findings, was not viewed as pertinent to this analytic process, due to the investigator's reflexivity as part of the data. Hence, reality was perceived as constantly in flux and changing (Morse, et al., 2002).

Transferability

Transferability is defined as the extent to which the findings have utility or applicability in other settings. This is determined by the extent to which researchers build upon previous knowledge and connect their findings to previous knowledge (Murphy et al., 1998). To avoid the reification of care, a notion of "tendencies" (not causal mechanisms) is assumed to govern social and health care culture in hospitals. Gubrium and Holstein (2000) describe interpretive practice as rendering various things and occurrences as recognizable in similar situations. The goal of interpretive phenomenology is not generalizability, but to infer qualitative distinctions having to do with intents and meanings. Hence, transferability is not determined upon structural relations, but on socially situated constructs that constitute the means and resources to enable a tendency for those same intents and meanings to be typified. Human activities and relations are, at least to some degree, structured, allowing for moderatum (semi-regular) generalizations (Williams, 2002).

This study employed three strategies to enhance transferability of findings to other similarly situated contexts. First, purposive sampling occurred for rich understanding of a homogenous sample of front-line cancer RNs from BMT services. The researchers suggest that although BMT services are particular to hematology oncology, they resonate with similar social situations where nurses experience similar existential concerns in their personal lives and their work.

Second, detailed excerpts from the data situate nurses' actions and stories in a context that allowed readers to make an assessment of interpretations about how findings resonate with their
own situations and concerns in practice. In other words, an interpretation of interpersonal relationships about the threat of patients’ mortality could only be transferable in as much as it resonated within other historical narratives, and within how readers were situated in similar health care situations.

Third, comparison of findings across empirical literature and practical ("lay") knowledge was discussed to enrich knowledge and validate formal theoretical understanding of the phenomenon across time and circumstances (Popay, Rogers, Williams, 1998).

**Ethical Considerations**

Prior to proceeding with this study, ethics approval was obtained from Research Ethics Boards of the hospital institution and at the University of Toronto (Appendix A). In what follows, informed consent was based on the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998) and on the *Guidelines on the Use of Human Subjects* (University of Toronto, 1979). Particular attention was paid to the ethical principles of respect for persons, from which flowed my ethical conviction of treating people as autonomous agents and reinforced my responsibilities to protect participants from harm (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979).

**Informed Consent**

Informed consent from all participants was given voluntarily and free of any coercion. To ensure this, nurse participants were not individually approached by the primary researcher for recruitment. Instead, initial contact was made to nurses via the intranet electronic mail messaging system in the hospital (Appendix B). Information about the study was provided by the primary researcher at staff meetings on the unit and in an “Explanation about the Study” sheet (Appendix
C and D). These information sheets were left in the staff lounges and in the nursing stations of
the units for nurses and other health care providers who had questions or concerns.

Once nurse participants initiated interest in the study (by e-mail or telephone) the primary
researcher contacted each participant by e-mail, telephone or in person to explain the study and
the expectations as a participant. Dates, times and locations (convenient to the participant) were
organized with each potential participant who was interested. At these meetings, I provided a full
explanation of the study including its purpose, methods of data collection, expectations of
participation, and the benefits and harms of participation. Participants were encouraged to ask
questions and any other information about the study. Each participant was assured that they were
free to participate, or not to participate, and their decision was confidential. Participants were
also assured that if they agreed to participate, they could withdraw from the study at any time
with no consequences.

After verbal consent, a consent form was signed (Appendix E), and time provided for
participants to ask further questions. Consent was emphasized as voluntary, confidential, and
ongoing during the study and in no way would it impact negatively on nurses who declined
participation at any time during any part of the study. Where one nurse withdrew from the study
before the interview, no data were used in association with his/her previous participation during
field observations on the unit.

The privacy of patients and the law related to personal health information were respected.
The researcher did not collect any patients' names or health information during observations of
the unit. Additionally, the researcher was governed under the Code of Ethics for Registered
Nurses (CNA, 2002) to maintain the confidentiality of all patient information given access to
shift exchange or team rounds. To reiterate, no requests of patients/families or physical contact
with patients or their families (during observations or interviews) occurred in this study.

Brochures about the research were left for nurse and allied health care providers informing them
about details of the study, ensuring confidentiality of all patient information, and providing contact information to answer any questions or concerns (Appendix C & D).

Privacy and Confidentiality

To ensure privacy, participant interviews were conducted in a private room and in a location of preference for the participant. Nurses participating in interviews were informed that they could refuse to answer any questions they felt uncomfortable answering by stating “pass,” and could withdraw from the study at any time.

The primary researcher was not an employee of the hospital and could not share any participant information identifying them to the Nurse Manager or other staff on the Bone Marrow Transplant Units. Several attempts were made to ensure that other health care providers involved in interactions with nurse participants were told about the study in at least two team meetings and informally on-site. Prior to each observational event, any individual (i.e., nurse or other health care provider) was informed that he/she could refuse to have his/her interactions observed without any explanation or repercussions.

To ensure confidentiality, nurse participants were asked to choose a pseudonym that was used for all documents, which might identify them, including transcripts, publications or public dissemination of the study and results. Participants were informed that only their pseudonym (not their actual names) would appear in transcripts shared with the research team. A master list with participants’ real names and their pseudonyms were kept separate from all data (Appendix K) at the hospital. Additionally, all the voice recordings that might potentially identify them and their consent forms were kept separate from all data in the hospital in a locked filing cabinet, in a locked office at an allied health care institution. All other identifying data were only to have the pseudonyms on them. All data, including interview transcripts, field notes, and my research journal were kept in a locked filing cabinet in a locked location at the Lawrence S. Bloomberg
Faculty of Nursing, University of Toronto. All computer files related to the study were kept under password protection entry. All data, including computer files, tapes and transcripts will be destroyed after seven years.

Data Storage and Management

Field notes and voice recorded interview transcriptions (using only pseudonyms) were copied and stored in a locked cabinet, in a locked office at the Lawrence S. Bloomberg Faculty of Nursing, University of Toronto. Transcribed interviews, typed notes, reflections, and preliminary analysis were stored in the computer software program of NVivo7 with private entry using a protected password and will be destroyed after 7 years.

Risks and Benefits

Inherent to any research process was the potential to cause harm to respondents, however, the level of risk was found to be minimal. Participants discussed personal and professional experiences, which did trigger an emotional response for many of them. These responses were not found to put them at any more risk than they experienced in their everyday work. Many even expressed that it offered them a place to voice issues of importance to them. Given my extensive mental health nursing training and experience, I was able to judge their anxiety and/or distress, and during those moments, I offered to pause or stop the interview in the interest of the participant. When it occurred, the participants were given appropriate emotional support. This included a reminder of their right to discontinue the interview, and/or to withdraw from the study, or reschedule the interview at another time. None of the participants stopped or withdrew participation during the interviews.

At the end of each individual interview, I explored the possibility of a referral for follow-up support and/or counseling with the participant. If any of the participants expressed that he/she
did want follow-up support, then my supervisor would be contacted to arrange a referral to an appropriate mental health clinician located in the downtown Toronto area. Also, as part of the study, the interviewer invited participants to follow-up via e-mail or phone if any problems arose. No participants requested the follow-up for support and/or counselling after their interview, suggesting that the interview process did not create any undue distress for participants than what they had already experienced and tolerated in their work.

**Dissemination of Findings**

Results emphasized thematic group analysis and only pseudonyms were used to maintain the confidentiality of participants’ identities. Benefits of reporting findings were considered to outweigh any potential risks. Careful attention to altering details of participants’ characteristics were consistently applied in order to minimize any risks. Findings have begun to be disseminated at educational seminars at the participating hospital, the affiliated teaching university, at a national cancer nursing conference (i.e., the Canadian Association of Nursing in Oncology), a national psychosocial oncology conference (i.e., the Canadian Association of Psychosocial Oncology), and at an international psychosocial oncology conference (i.e., the International Psychosocial Oncology Society). As a result of this thesis, a literature review about existential care was published in the European Journal of Cancer Care. Plans are in place to publish two more manuscripts based on these thesis findings and their implications in peer-reviewed international journals (i.e., the Journal of Palliative and Supportive Care and the Journal of Sociology in Health and Illness).

**Summary**

The main purpose of this doctoral research was to use interpretive phenomenology to explore nurses' lived experiences of being with cancer patients who face the threat of mortality
on two bone marrow transplant units of one institution in Canada. In particular, the study was
guided by four questions: 1) To uncover how nurses experience the threat of patients’ mortality;
2) To illuminate how nurses engage in these issues (if so); 3) To explore how the context of
inpatient bone marrow transplant unit situates nurses' with cancer patients who face the threat of
mortality; and 4) To provide ways nurses coped with their work.

Individual interviews and field notes were given primacy of data, but I supplemented
these with focused observations in public areas of the participating units to understand the taken-
for-granted background of nursing interactions, routines of care, and artifacts on the units.
Interpretation of the data involved multiple readings, to continually move back and forth to
analyze parts and the whole of the text. In doing so, I used two strategies, thematic analysis and
the hermeneutic circle, to name meanings of nurses’ actions, map patterns, establish descriptive
themes, and develop an interpretive commentary. Several strategies ensured rigor defined for this
study as credibility, plausibility, including the investigator's reflexivity and responsiveness, and
transferability of findings. Throughout the study, attention was paid to an ethical commitment
that adhered to principles of informed consent, privacy and confidentiality, and balancing
potential risks and benefits to participants.
CHAPTER VI:

FINDINGS
The purpose of the study was to explore nurses’ experiences of being with cancer patients who faced the threat of mortality. These experiences were in the context of oncology services where bone marrow transplantations occurred. Bone marrow transplantations offered patients a last hope of a cure in the fight against cancer. As such, it offered patients an alternative to certain death. While some patients experienced serious complications of treatment and were expected to die, they sometimes miraculously recovered. As such, nurses’ concern to “fight cancer” continued almost until patients imminently faced death.

Given these circumstances, it is not surprising that the fight against cancer meaningfully oriented their situation and directed their involvement with patients. However, nurses expressed almost as much concern about their felt responsibility to prepare patients to “let go.” Preparing patients to “let go” was emphasized in expressions of “if things don’t go well,” or when patients were given “false hope.” As such, letting go did not resonate with giving up or abandoning life. Rather, letting go reflected nurses’ intentions to release patients from the requirements to adhere to the norms of a curative culture that would entail continuation of treatment. While concerns of “fighting cancer while preparing patients to let go” were seemingly in conflict, together, they formed the meaning behind intentions to protect patients from meaningless suffering.

The experiences of fighting cancer while preparing for the possibility of letting go was the common theme throughout all of the nurses’ narratives, more specifically characterized by four sub-themes and their respective elements illustrated in Appendix M:

1) Working within the culture of cure and the possibilities of patients dying had three elements, a) the culture of cure, b) understanding the possibility of patients dying, and c) challenges encountered in recognizing the possibility of patients dying.

2) Concern about “bursting the bubble of hope” had three elements, a) watching over patients’ bubble of hope, b) recognizing patterns of dying, and c) reluctance to burst the bubble of hope.
3) Whether to and how to respond to patients’ distress and dying had two elements, each with its own intentions, first, whether to respond was characterized by: a) emotional attunement to fight or to let go, in addition to situated knowledge, capacity, and perceived control to instill the patients’ fight or to let go, and second, how nurses responded in responsive skills of involvement characterized by: b) communication about the threat of mortality and death, letting be and supporting families to let go, managing technology and preventing technological intrusions to patients, and striving for patients to have easier deaths.

4) Coping with patient involvement had three elements, a) acknowledging the threat of one’s own (nurse’s) mortality, b) tempering patient involvement, which oscillated between avoiding and detaching self from patient involvement, and c) releasing tension created by their conflicting concerns, which temporally progressed till patients died.

Note that I use pseudonyms in these findings to protect nurses’ anonymity.

Fighting Cancer While Preparing for the Possibility of Letting Go

Embedded in all of the nurses’ texts was their common concern to instill a fighting spirit in patients, while recognizing that at any point they may be preparing the patient to let go. In relation to instilling a fighting spirit, nurses “cheered” patients on and reinforced the idea that they were a part of the life-saving team. This encouragement bolstered patients’ will and their felt responsibility to fight cancer.

Because it’s the beginning and most people come in very healthy. And you’re not really dealing with those side effects yet, that could be life-threatening. So, my care is very hopeful. ‘You’re going to make it through this. I’m going to be here. We’re going to do this together,’ and things like that. (Zoey, allo unit)

You have to encourage them constantly and say ‘No, you're not going to give up. You're going to fight it. It's a hard time, but you're going to do all these things. (Ann, allo unit)

As treatment progressed, nurses felt compelled to respond to the salient aspects of patients’ suffering, often triggered by complications of treatment.
I don't know if there's any scientific proof about this—but when they engraft early they seem to have a much higher tendency to be the ones that are going to have the real bad GVH. The rule of thumb is usually you'll see white count first, then the platelets, then the haemoglobin, the red cells will go, so you know... during that period, where they’ve been transplanted but they have not engrafted, nothing has started to grow yet, they are totally dependent on transfusion. That’s the most dangerous time for infections, septicemia, that sort of thing. (Shania- allo unit)

Nurses’ sense of meaning in their work eroded when, as they focused on patient recovery, they witnessed patients’ suffering. Nurses became concerned not about patients’ dying, but about patients losing their will to fight their cancer. During these moments, nurses, such as Potter, expressed that the provision of care was more “draining.” At times, the nurses felt depleted and at a loss as to, whether or not, they alone could continue to “cheer patients on” when they had lost their will to fight.

There's only so much rah-rah siss boom bah that anybody has...especially if they're not willing to take it, then you're cheering for no one, really, because if they're not cheering for themselves...so that I found more draining. Not that I didn’t like the work, it’s just emotionally heavier. (Potter, auto unit)

According to the nurses, such as Megan and Ann, patients’ sense of fighting cancer was associated with enduring treatment, and therefore having a better chance of recovery. If patients had lost or exhibited a lack of fighting spirit, nurses seemed to interpret this as an indication that patients were no longer choosing to fight cancer and felt that they risked death.

Patients’ attitude to fight is really good with the prognosis. Most of the time, we have some who with whatever positive thinking they have they still didn’t make it really well, but most of the time, those people who are really determined to fight it,... usually do really well. (Megan, auto unit)

You've got to hold onto the treatment and you've got to put all your will into that, to fight it. But if you give up in your heart, you cannot fight anything. If you lose the passion, if you lose the will inside you, you can pump them with everything, but they'll still die. (Ann, allo unit)

While I understood that nurses felt some responsibility for instilling a fighting spirit and helping patients transcend their suffering during the course of treatment, I began to wonder when, how, and with whom nurses discussed ways to prepare patients for possible death.
The persistent theme was nurses’ conflicted feelings to sustain life while situated to see the possibility that patients/families, and they, themselves, may have to let go of hope for recovery, if and when, patients approached the limits of curative medicine. Some nurses perceived that by preparing patients/families for the possibility of death they were able to prevent unnecessary suffering.

You need to be prepared if things don't go well, for what's going to happen right? How are you going to handle it? But also you need to have a little bit of hope too, to like go on right? I always try to stress balance, before…both. But I don't want them [families] just to be so hopeful that when the patient dies or something like that happens, that they [families] are like shocked. (Tess, allo unit)

Those who are really emotionally not prepared are hard because they have high anxiety levels. Those are really difficult patients, because we’re not only concerned about their physical but their emotional and psychological well-being. (Odi, auto unit)

While some nurses more strongly adhered to fulfilling life-sustaining goals almost till patients died, others modified intents motivated by a need to advocate for preparing patients for the possibility of the end of their lives. This latter concern shifted nurses’ commitment to not only sustain life, but supported each patient’s freedom to judge what was important, and to make personal choices to deal with his/her current state. In the following excerpts, Betty and Ann advocated for their patients’ wishes over and above the families’ or physicians’ wishes.

Well, I don’t believe in keeping information from patients. They have a legal right and an ethical right to know. Yes, you can respect the family wishes, if they don’t want the patient to know, but that really bothers me, because the patient does know. The patient does know and they have a legal… they're age of consent, they're 18 or over, especially the new privacy laws. (Betty, allo unit)

Somehow as a nurse, you take the patient's side, because I think you make a bond with them. It's them that you are there for. It's their wishes that you want, not the family's, not the doctors. (Ann, allo unit)

Both the allo and auto units followed a primary nursing model that facilitated nurses to have a sense of connection to, and familiarity with, patients and their families. This model assigned primary responsibility to a particular nurse for watching over each patient’s everyday care. So, nurses filled a unique role on the life-saving team, in that other team members regularly
consulted them about how to direct or provide the care of particular patients and their families.

Nurses spoke about their primary patients as persons and underlined how familiarity with the person generated important individual meanings that were specific to the relationship, rather than being related solely to the procedural needs of care.

It's usually primary nursing we have here and I think it's a very good idea because...there's a, I wouldn't say bond, but there's a familiarity that you get with the family and the patient. And you get to know each other very well. (Shania, allo unit)

It's why the primary thing is really important because when you're primary you'll get to know them really well, you'll know their situation and you know the family and that sort of thing. (Zhanna, allo unit)

Nurses expressed anxiety about patients asking their opinion about what to do when given choices about treatment. I sensed that this discomfort was not so much about how to answer, but was based on a concern of why and whether patients/families understood the serious complications and fatal consequences of their treatments.

Because they've accepted the treatment, they are grabbing onto the hope, and I'm reinforcing that. If a patient then decides to not have the treatment, if they say they’ve failed their induction and they failed reinduction, and then they're offered a study – to go on the study, some will grab onto it, some will just say no. Then I'll reinforce that, saying ‘You know, this is probably a good choice for you.’ Sometimes I get them to think about it. It depends. I have to always gauge my patients to see what they want. (Raylene, auto unit)

In preparing patients to let go, nurses often spoke about their obligation not to give false reassurance. They compared their actions against those of doctors, some of whom did not acknowledge patients’ suffering associated with a sense of meaning for the patient. In the following narratives, Snook and Julia describe doctors’ behaviour as “brutally frank, very blunt and cutting to the chase,” or in contrast, giving “false hope.” To these nurses, these approaches augmented patients’ feelings of helplessness, anger, and/or disappointment. In doing so, “these doctors exacerbated patients’ suffering and missed opportunities to facilitate an easier death.”

These episodes appeared to result in nurses feeling frustrated and suffering a sense of powerlessness.
She [spouse of patient] goes [whispering] ‘Don’t let him talk to him like that. Don’t let him talk to him like that.’ I said ‘Well, there's nothing I can do. This is the medical team passing on information as they see it. I'll go talk to him later.’ After the doctors walked out, he [the patient] grabbed the oxygen and he goes ‘Well I guess I won't need this anymore.’ I fell apart…All this time when he was saying that, I was holding back the tears. And then I left. (Snook, allo unit)

No, he [the doctor] kept giving the family a kind of false hope. He's going to try this chemo and try that chemo. He did try another chemo which didn’t work for her….She died after a while. (Julia, auto unit)

At this point, I considered the meanings and importance nurses gave to quality of life that patients experienced. Ideas of life and living took on conceptually different meanings within nurses’ narratives. Instilling hope for recovery and/or symptom management was a salient ethical act for nurses, as was instilling hope for what they referred to as an “easier” death. When there were discussions about both intents, nurses, patients, and their families shared a sense of responsibility for fighting cancer as well as for preparing patients to let go. At this point, hope for cure, recovery, and/or symptom management seemed as meaningful and relevant to nurses as instilling hope for an easier death. These coexisting and conflicting concerns of nurses motivated not only wanting to prevent patients’ deaths, but wanting to protect the opportunity for maintaining a sense of meaning in patients’ experiences of existential distress and possible dying. A sense of meaning in patients’ suffering guided the direction of nurses’ concern, weighed to both fulfill fighting cancer while preparing for the possibility of letting go, to different degrees. Nevertheless, the dominant discourse was the curative culture that provided common background meaning for all nurse-patient involvement and shaped their responses to patients’ situations.
Working within the Culture of Cure and the Possibilities of Patients Dying

The Culture of Cure

My observational field notes (below) describe nurses’ sense of competence tied to implicit demands to master life-saving tasks. I interpreted that nurse participants implicitly experienced challenges in how they constituted their professional identity to save lives when people faced an uncertain and ambiguous future, as the following notes will reveal.

The Allogeneic (allo) Bone Marrow Transplantation Unit

I walked off the elevator and entered the allo unit through two closed double doors. The doors physically separated the unit from the rest of the hospital. Beyond the double doors, I walked through a hallway that turned to face the nursing station. Here was the working engine of the unit. Medical machinery was crowded on top of counters and countertops that bordered the space (e.g., three computers, a printer, call bell monitors, a blood transport tube). Medical tools were strategically located (e.g., intravenous poles held several items, such as mixtures of fluid, blue hospital gowns, rubber gloves, and paper tape). A crash cart for emergencies was located near the medication dispensing machines and a refrigerator, across from the nurses’ station.

Halls held an overflow of equipment (e.g., hampers, wheelchairs, blood pressure cuffs, clean linen on carts, weight machines). Everywhere, space was crowded. Bedside tables from the patient rooms extended counter space for patient charts and medications.

Clinicians frequently congregated in the nursing station, absorbed in discussions about patient care and in documenting their work. Documents in the nursing station included a binder entitled “Newly Diagnosed Patient Education.” This binder included “Consent to Treatment” forms designating “Substitute Decision Makers.” Another shelf held death certificates.

As I walked through the halls, the smell of creamed corn wafted down. One nurse told me that this smell came from patients receiving their bone marrow transplants. I imagined that this
smell triggered angst for other patients nearby who anticipated or had had the treatment. Patients remained in their rooms for most of the day with their curtains and doors closed, rarely venturing into the patient lounge. A few patients’ doors hung “Protective Isolation” signs on them. A box of gloves, masks, Oxy5 wipes, and a wheelchair were outside one of the patient’s doors. Six wash stations (three in each of the two halls) were built into the walls, and bottles of hand sanitizer perched on the railings outside several patients’ rooms.

Across from the nursing station was a room into which various staff often retreated for momentary solace from their work. Here they could store their personal items in lockers, eat, and talk about their lives outside the hospital. Yet even in the staff room, a few artifacts on the bulletin boards displayed symbolic acknowledgement of death and appreciative gestures of staffs’ work: obituaries, thank you cards from patients who had been discharged or from relatives of those who had died, a poem entitled “Angels,” and a glass display case with two nurse figurines inside. One had an angel standing behind the nurse. Above it, there was a poem entitled, “A nurse’s prayer.”

*The Autologous (auto) Bone Marrow Transplant Unit*

When I entered the auto BMT unit, the double doors were open. Unlike the allo BMT unit, this open entrance invited people to the nursing station. The nursing station was an area bounded by low counters and covered with medical equipment. Patients were visible walking the hallways while pulling their intravenous poles and monitoring machines. I saw patients conversing with others in the designated patient lounge. Doors to patients’ rooms were often left ajar. Additionally, in contrast to the allo BMT unit, some of auto BMT rooms were semi-private.

In the same way as the allo BMT unit, the auto BMT unit held tools to assess and respond to events surrounding death and dying. Across from the nursing station, there was a crash cart. I was told, however, that the cart was “not really considered a crash cart. We don’t have a
defibrillator,” stated Carrie. Flyers posted on the nursing station and staff conference room walls predominantly gave information on safety and infection surveillance (e.g., CPR training, incident report changes) or information about treatment-related side effects (e.g., oral mucositis). Inside the nursing station, a bible was tucked away on the top shelf of a book cabinet, behind the ward clerk’s chair. Documentation lined one of the walls of the nursing station. On the highest shelf of the wall, there were forms termed “Living Wills/Advance Care Planning, Do Not Resuscitate Addendum,” and “Power of Attorney.” Additionally, there was a package of forms labeled “Death Packages.” These packages each contained a “Medical Certificate of Death,” a template of a letter to inform the family doctor of the death of patients, a consent form for an autopsy, and an information sheet for discussing organ and/or tissue donation with a “Substitute Decision Maker.”

Encountering Differences in Treatment Units

The artifacts in the allo unit conveyed that despite staffs’ best efforts to save lives, sometimes patients did die. I imagined that heightened awareness to the risk of the risk death and dying increased the emotional burden to save lives. There were plaques on the walls bestowing space as gifts from patients and their families. The spaces included the nurses’ station, patient rooms, the conference room, the staff lounge, the “patient-care pod,” the patient lounge, the procedure room, and the nutrition room. The walls held posters and paintings the full length of the hallway. These posters conveyed inspirational messages, such as “Dare to Soar,” “Focus” and “Obstacles are those frightful things you see when you fail to focus on your goals.” A dream catcher encased in glass on a wall in the nursing station held a gold-plated inscription: “Courage, hope, and inspiration.” The paintings, often originals were donated in memory of patients, who were once on the unit and had died. I ascertained this when I noticed that at least six of the paintings or photographs had plaques with the year of patients birth and death. Paintings
imparted meanings unique to the individuals: a hand-drawn cartoon character, an angelic child holding a lamb, or an empty row boat at the edge of a lake (Appendix L for photographs of the artwork). Nurse participants, Shania and Zhanna, spontaneously made comments about the artifacts. Both told me that the paintings on the walls reminded them of the emotional burden associated with a heightened awareness of the risk of death and dying on the allo BMT unit.

I don’t really look at it [pictures on the walls], but I know it's depressing for other patients. Because when they come on the floor, when they're still healthy…..they sort of walk around the floor and a lot of patients start to make comments about…‘Oh, all these people have died, nobody still’…And they sort of think well, what's the point, sort of thing. So I know they find it depressing, like some of them at least. (Zhanna, allo unit)

In contrast to the allo BMT unit, the auto BMT unit had far fewer public artifacts conveying risks of death and dying. Unlike the allo BMT unit, there were no wash stations built in the hallways, but hand sanitizer bottles were perched on railings alongside patient rooms. Two pictures hung on the walls: paintings of landscapes, of which one was dedicated to staff. Notwithstanding this, there was a guide for advance care planning in the patients’ lounge acknowledging the potential for death. There was also a framed mural quilted by patients. The mural held cards with handwritten notes and poetry about hope and creating a “safe haven.” Additionally, in the staff conference room, there were two newspaper obituaries taped on the wall near the light switch, and two thank you cards from families. The bulletin board had a brochure on accessing community palliative care services. Hence, the threat of mortality was more visible on the walls of the allo BMT unit as compared to the auto BMT unit, reflective of the greater statistical risk of death due to complications of allo BMTs.

**Understanding the Possibilities of Patients Dying**

In spite of the above described differences between the two BMT units, nurses shared a cultural understanding of the “possibilities of patients dying.” This was, in part, informed by
similarities in the potential risk of early relapse of hematological malignancies and the relatively high potential for treatment-related morbidity and mortality.

Participating nurses perceived treatment-related complications as possibly life threatening. Megan stated that her experiences did not fit with what she read in the research literature, in terms of the rates of recovery from bone marrow transplantation.

The literature has all these numbers that say 90% is...would go in remissions, stuff like that. Not really, no, but then I was talking with one of the doctors who was saying it’s just because we’re a myeloma floor that we see all of them and then we see more deaths than is usual...but based on a general population it’s still very curable...Because our population here is more concentrated on this kind of disease, that’s why we see more deaths and the literature doesn’t reflect that. (Megan, auto unit)

Megan’s experience of “more deaths than is usual” situated her concern with fighting cancer. Her experience evoked questions about the appropriateness of her intuitions against her agency to save lives. In effect, nurses understood mortality based on the ways that they were intuitively engaged by the possibility of patients dying and this intuition forewarned them of whether or if patients would recover.

As members of a life-saving team, nurses rarely openly disclosed their acknowledgement of the threat of patients’ mortality. They tended to selectively impart information about bone-transplant technology that implied probable survival. Within the culture, nurses were required to visibly build confidence in the authority of treatment.

You just tell them [patients], ‘It’s different from person to person. You're different from him, from her. So don’t worry. Your time will come. Your counts will come up sooner or later. (Ody, auto unit)

You have to come to accept that you are with the team that’s actually trying to help people and that what you are doing makes sense. There are some hopes you take to heart. So, when patients ask me, ‘What do you think? Do you think I should be doing this?’ I would say ‘Your doctor has made the right decision.’ Because you have to be a team. You have to work well together. You can’t instill ideas in the patient’s mind that this is not a good idea, or that this might even be a questionable idea. (Birdygirl, auto unit)

While Birdygirl may have questioned treatment, she continued to endorse her commitment towards strengthening patients’ will to conquer cancer. This was not without
empathic reflection and concern for the possibility that patients might suffer from treatment complications and die.

I feel sorry that patients had to go through some of those treatments, but we tried to help them as best we could. And now I see that there are some cases that do well, and many times, I would do the same thing too. Because you don’t want to give up. There's just… modern medicine being what it is, there are some hopes that you can take to heart. (Birdygirl, auto unit)

Underlying Birdygirl’s story and others’ (below) was the nurses’ concern to not give up helping patients fight their cancers, within this specific setting, regardless of their knowledge that a patient may not survive. I was struck by the reluctance to acknowledge the possibility of death when freedom “to do something” (anything), commonly meant risking patients’ quality of lives.

People don't come here to die. They don't come here to die. If it was a palliative care unit, then it's something you would…but they come here to be treated. If in that process it's unsuccessful, then you…but then like Dr. X said if there's a 0.001% chance that something we do for them is going to reverse that, we do it…You’re doing the best you can and not giving up. (Snook, allo unit)

Nurses’ strong allegiance to the life-saving team created particular notions of proper care. Notions of what was proper stemmed from providing “the last or only hope” to patients for more time to live. Hence, proper care prioritized the technical tasks that might extend patients’ survival.

We've just managed to get them into remission. Some of them have relapsed so many times. When you keep relapsing, the chances are less and less. So consequently, if they don't have this transplant, they die. That's what I mean it's the only hope for them. (Ann, allo unit)

*Challenges Encountered in Recognizing the Possibilities of Patients Dying*

Life-sustaining technology engendered hope for a cure, recovery, or symptom management. These cultural beliefs did, in themselves, possibly veil the recognition and acknowledgement of the threat of patients’ mortality and possibilities of patients dying. Examples of this challenge were evident when physicians minimized or dismissed nurses’ concerns about the consequences of biomedical treatment—often while nurses knew doing so...
meant patients experienced distress and would be unprepared for possibilities of imminent death. In those situations, nurses expressed a concern to initiate a type of advance directive to prevent cardiopulmonary resuscitation (CPR), that is, Do Not Resuscitate (DNR) orders, rather than continue to give patients unrealistic or false hope.

One of the other doctors was in there. And he pretty much instilled all of this hope and optimism, and pretty much guaranteed her that, if we can get her over this hump then yeah, ‘We’ll get you into that study.’ Me sitting there knowing that, should she get that study drug, we will kill her. Because it was so strong and she’s so weak, physically. There’s no fight that her body would’ve been able to win. I went into this talk thinking we were going to do the code discussion and there was no concept of code discussion, DNR status, at all. (Potter, auto unit)

In concealing the possibility of patients dying, many of the nurses expressed tension and conflict among staff and described disagreements about what was “best” for patients facing the end of their lives. This conflict occurred between disciplines, such as between nurses and physicians, but also occurred among nurses.

I was just so angry. I went to the doctor and I said ‘Dr. X, why are we doing this. Why are we doing this? Why don't we just keep him comfortable and just…?’ He said to me ‘If there's .0001% chance that we can give him something that will reverse this, we have to take the chance because we brought them to this stage.’ I understood their reasoning behind it because we did this to him. I understood where he was coming from. I didn't agree with it. (Snook, allo unit)

There's a lot of conflict within the nurses on [unit’s name], and I'm sure you picked up on that. I mean, because the conflict can be pretty intense. And it’s caused a lot of issues over the years…On the other hand, I've never worked on a unit where there's been so much conflict. (Betty, allo unit)

Despite the policy of caring for patients until the end of their lives, talk that confronted patients’ mortality and the issue of having to let go was experienced as being very challenging. Discussions of this kind were described as occurring more informally when nurses had the time and were comfortable with it, versus through more formal means. Many nurses faced obstacles around engaging in such discussions or in learning how to facilitate patients “letting go.”

I don’t feel like we do talk about it [the threat of mortality] that often at work. We don’t really. We're there for each other, but sometimes we don’t sit there. (Julie, allo unit)
But I don’t think that you are able to do that if somebody then doesn’t help you deal with the suffering and make sense of it and come to terms with it. It's a very painful thing to have to go through on a regular basis, and to put it in perspective. (Kandy, allo and auto units)

Nurses did not have resources, that is, time or support, to negotiate interdisciplinary discussions around their conflicting concerns, and develop skills to respond to patients’/families’ distress. There were regular monthly meetings led by the hospital chaplain, yet only a few nurses mentioned that they attended them. Conversely, a few nurses mentioned that the meetings were a helpful place to discuss their experiences of loss and grief.

I think once a month or once every few months they do it. We used to have and we still do have chaplain…When we first moved here…sessions were once a week where we have tea and we just discuss anything. A lot of times it was just whatever difficulties we may be having on the unit. (Snook, allo unit)

I often witnessed staff consult Intensive Care Unit (ICU) specialists from a neighboring hospital about potential transfers of patients. However, only once did I observe a staff consult palliative care specialists for a potential transfer.

No, we've always had an issue on [name of unit] unfortunately…They give this patient the idea that he/she may pull through this. A referral to the palliative care is virtually unheard of on the floor. (Shania, allo unit)

Nurses were aware of how the culture prioritized technical demands at the expense of patients’ existential needs. Some nurses, such as Potter (below), discerned that health care disciplines, such as medicine, failed to acknowledge what was not “fixable,” and devalued nursing involvement leading these discussions and making a case for decisions to occur with patients/families.

She’s now jaundiced, she’s a walking yellow woman, and I believe yesterday in the notes, it said that she’ll be resuscitated and go to ICU should the problem at hand be acute. But if the doctors believe that it’s not a fixable problem, then no, she doesn’t want to go to ICU. So really you’ve got your hand in both pots. (Potter, auto unit)

Knowledge and techniques that governed the treatment of bone marrow transplantation took precedent over an approach that responded to the existential needs of patients and their
families. Kandy expressed a tendency to do “what was expected,” rather than talk openly about addressing the threat of patients’ mortality.

When things aren't fixable, they're not really sure what to do, or what to say because they're always trying to say ‘We're going to try this, and we're going to fix that. (Julie, allo unit)

So I think basically, you've got to say, ‘Well if nursing needs to be more technical, then let's do that, if that’s what's rewarded and that’s the expectation.’ But if we're looking at it being holistic, then it needs to be recognized that this [supportive care] is the hidden work involved for nurses. (Kandy, auto & allo units)

While Kandy suggested that supportive care was not measured or valued in the same way as their technical skills, she made reference to times she changed her focus to existential elements of caregiving after basic needs of physical comfort were met.

From the patient's perspective, they want the comfort, they want their basic needs to be met first, and when those needs are actually met, you can go beyond that…So you have to meet those basic needs first for any of our patients. (Kandy, auto and allo units)

The matter of when was the appropriate moment to focus more on supportive care needs was a contentious issue. For example, a Do Not Resuscitate (DNR) order was important because it publicly declared that the patient was possibly near death. As such, nurses’ requests to physicians for a DNR order signified an opportunity for nurses to talk openly to patients and their families to prepare for the possibility of death and engage in their threat of mortality. Samantha admitted that the medical team often avoided or even rejected talk of DNR orders, suggesting that they were premature. However, when there were no DNR orders, nurses experienced these factors as impeding opportunities for talk that could alleviate distress for families and nurses particularly when both parties recognized imminent death. As a consequence, nurses were often the ones that advocated for DNR orders, which removed the mechanical intrusion and control over life.

So a lot of times we’re saying ‘This person doesn’t have DNR [Do Not Resuscitate] status. Do you want to discuss it?’ And then they're [doctors are] saying ‘Well, we just started the treatment, and we know how it's going to go. And it would be kind of too early to bring up the topic now.’ But we say ‘Oh well, what if something happens? We
need to know.’ So a lot of times it's not 'til a lot later. Later than we [nurses] would like, then that it seems like the death is almost imminent, then they will bring up the issue. (Samantha, auto unit)

While many patients did have DNR orders, nurses still expressed confusion when deciphering and following them. More specifically, nurses expressed frustration with DNR orders which did not clearly reflect what patients/families wanted during a medical emergency. As a result, nurses either had to clarify what DNR orders meant to patients/families or ask the physicians to do this. When clarification did not occur in time, nurses felt conflicted in knowing what to do when patients were imminently dying. Sometimes, they witnessed other medical staff ordering CPR on patients who had DNR orders.

The problem with our patients is that…a lot of time we have to do the DNR sort of talk with them. And doctors really don’t go through that. So that’s the hard part… They [doctors] don’t really get it across. They go to talk to them [patients/families] and then they never really get it across how bad the situation is. (Zhanna, allo unit)

They [doctors]…will say, ‘Oh, you know what, I don’t think the trip to the ICU will be beneficial for you, because you may…you don’t want tubes stuck in you…And you don’t want anybody to pump your chest, right?’ And then, ‘Well, since you put it that way then,’ the patient will say, ‘No, I don’t want that.’ And then they [doctors] come out all right with the order saying, ‘Do not resuscitate as per discussion with the patient.’ But it depends on how you worded it. Actually, the patient probably understood it differently, because that’s what happened with one of our patients before. They understood DNR as something else. They understood that talk with the doctor as something else. (Samantha, auto unit)

They [the doctors] might have ‘the talk’ wherein the event that an emergency happens, what would you like us to do. And we can maybe get a DNR order, but there is also variations within DNR…I mean, we've had doctors call codes on people who were made DNR. (Shania, allo unit)

In short, life-saving technology competed with space, time, and resources to develop skills of how to respond to patients’ existential needs. Indeed, I considered the lack of formal acknowledgement of the threat of patients’ mortality surprising given the hospital’s mission statement espousing patient-centered care. Such care implied direction by the patients and need for their continuous and consistent involvement in decisions to the end of life.
A lot of the times when they come back, if they really end up being sick, we do a lot of DNRs [Do Not Resuscitate Orders]. And when that happens we keep them on our floor, generally. Because, even if they're going to palliative [care] we usually keep them on our floor because they’ve been there for so long. Sometimes we transfer them, but not often. (Zhanna, allo unit)

Concern About “Bursting the Bubble of Hope”

The manner in which nurses described how patients died reflected their concern about “bursting the bubble of hope,” as the nurse, Carrie, put it. Their mannerisms were revealed, when in nurses’ narratives, their speech changed. They spoke quietly or loudly, avoided eye contact, sped up or slowed their talking, and cried about how patients “lost hope” and died. Sometimes they sought understanding from me or questioned their own actions. Nurses seldom used the words “dead” or “died,” instead they said that the patient had “passed away” or paused in silence to indicate the death or dying of patients. Within their stance, I interpreted a tendency to try to maintain hope for recovery and a concern of being the one to “burst the bubble.”

Watching over Patients’ Bubble of Hope

Nurses were situated closely to patients and “watched over” them. In doing so, nurses tried to enhance patients’ sense of personal control and capacity to define life as meaningful. As the designated “come-to-people,” nurses were a ready source of information and extended patients’ agency. I observed that patients and families came to nurses when they could not talk to anyone else. They came to nurses for information, with questions, and for clarification of what others had told them. Other clinicians sought nurses’ counsel about patients as well. Nurses were aware that their ability to translate across disciplines made them indispensable members of the life-saving team. While nurses did not hold as much authority over biomedical treatment as physicians, they did have authority seeing and understanding patients’ situations and translating this to patients or to others.
The family will ask the nurse all that stuff. What do I do, you know what happens now? And after he dies, where does his or her body go and how do I…and so you have to have some answers, if somebody's dying at home, who do they call? Do they call 911? Do they call their family doctor, they just…I feel like the nurse, you wear so many hats. You're the come-to person for all their concerns and questions. (Julie, allo unit)

I went to Dr. X afterwards, and I said, ‘So what was the point of the conversation?’ And he basically said, ‘Well, to tell her that the treatment we're giving her has not had a lot of success, and it doesn’t look good.’ And I said, ‘Really? She didn’t get any of that from the conversation. She really doesn’t know what happened.’ So he ended speaking to her…but I mean, that sort of happens a lot. (Zhanna, allo unit)

Nurses attempted to mobilize services for patients as needed and requested, and exhibited a kind of unique, personal monitoring, which included at times an advocacy role in relation to preserving the greatest authenticity for the patient. Participating nurses expressed a sense of "where the patient was at" and offered, what they could, when it needed in accordance to the patients’ desires/ wishes/ needs. This capacity to connect patients was the key in linking them and their families to resources. In other words, nurses fulfilled a navigation role in assisting patients through the cancer journey within the hospital system.

And then, sometimes if they need other information or other things – some patients come to work out, and I find they don’t know that we had a gym downstairs, with physio, that if you just hook them up – the younger patients that come, they just want an outlet, you know? So I'm saying, ‘This is available.’ …Social work can connect them with a buddy. Sometimes I find setting them up with someone, like a buddy system works really well, so I've done that with patients a lot. (Carrie, auto unit)

The nurses’ concern about bursting the bubble of hope compelled them to attune to cues of when patients came close to death. Nurses were vigilant to monitoring the potential for a quick change in a patient’s physical status.

Yeah. Well the patient is really like a ticking bomb, if you could say. You wouldn’t know when she’s going to…Yeah because…most of the time you know that that patient is so sick, they're not going to come back. (Megan, auto unit)

Nurses were concerned that advance directives eroded patients’ hope for recovery even though they protected patients’ health care preferences for the event that patients became incompetent to make decisions in the future. Nurses’ concerns seemed to be intuitive and were
related to being in sync with whether patients were ready to discuss the consequences of bursting the bubble of hope. So, while I understood that advance directives were based on a concern to have patients define the limits of their own suffering, nurses worried that the advance directives might inadvertently push patients to be aware of their threat of mortality and their possibility of dying. Some nurses expressed concern that open discussions of medical risks might disrupt the process to remain committed to hopes of “beating cancer.”

Sometimes it's a hard thing because they're like ‘Whoa!’ Right? But it's probably the best time because they're still well, they can think clearly in their head, like what do I want done if I'm so sick. Do I want to be intubated? Do I want…how much do I want done to me? But for the family too, it's the best thing because then it's such a hard thing for the family if they haven't discussed these issues with the patient and they have to make all the decisions. (Tess, allo unit)

Nurses were sensitive to how much information they ought to provide, and often conferred with other health professionals, particularly doctors, for guidance. Some nurses feared that too much information could overwhelm some patients and add to their emotional distress.

There's all kinds of risks. There's the physical risks, the falling, the risk of aspirating when you can't swallow, when you've got mucositis. I mean there's thousands of risks out there. Picking up things…and emotional hardship. It just puts you down so far that you can't fight your way back up and you have to help yourself, somewhat, or you won't survive. So I have to be there physically to tend to all those things. That’s the way I see it. And I have to study enough of the patient history, which I try to do. (Birdygirl, auto unit)

Recognizing Patterns of Dying

Nurses’ narratives revealed intuitive knowledge of patterns and changes in patients. As such, some nurses had premonitions of a timeline or phase of patients’ deaths.

In the beginning, it's not intuitive, but at the point you've seen so much of it, that you know. I've had people come into the door, even before the transplant and you just look at them and think, no, this is the wrong thing for you to be doing. Get your suitcase. There's the exit door, use it, because we're going to kill you. (Shania, allo unit)

There's a lot of times when you know the patient's not going to make it. I mean, there's times when we've seen people come in and said, ‘Oh they're not going to walk out of here.’ And a couple times, they have. But on the whole when you first come and you hear people say, ‘Oh, they're not going to make it,’ you think, ‘Oh yeah, whatever. You don’t know what you're talking about.’ But eventually you start making those kinds of… assumptions, too. (Zhanna, allo unit)
Consequently, nurses tried to prepare themselves for the moment when patients would die. Nurses’ language reflected attempts to distinguish patterns, as Zoey stated (below), “to different kind of sickness;” distinctions that allow them to anticipate and to know when patients approached the end of their lives.

There’s a different kind of sick between the patients that are going through the transplant process and the patients that come back post-transplant with complications. They’re acutely complex after the transplant, but they’re all problems that we expect, that we can plan for, that we know the treatments for, we know what to do. But it seems like the post-transplant patients, it’s kind of like a cash-grab sometimes. You’d know basically what to do for graft-versus-host of the gut, but when it’s not resolved and the patients are in pain and you’re giving them blood products and all these meds, the problems mount. (Zoey, allo unit)

Nurses often knew before others (even patients), when patients were moving toward the end-of-life phase. They expressed in-depth knowledge of the shift from the patients’ normal state to a dying process, from evidence that was both objective and intuitive.

I hadn't seen him in a week or so, but I went into the room and I just knew that he would probably die in two days, two to three days. (Julie, allo unit)

I knew he was going… slipping fast, fast, fast, fast, fast. But I know, that day when I went there I didn’t think he was going to die in an hour or so. But when I was there and I didn’t move from there. And I thought, ‘Oh my god, he’s going to go, he’s going to go.’ (Chopin, auto unit).

Nurses attuned to changes in patients’ state of hope and sense of fight. At times, they discerned that their patients may be giving up hope of recovery prematurely. Nurses expressed concern about their patients’ expressions of (verbal or nonverbal) hopelessness and helplessness. The narrative below illustrates an example of this kind of meaning, which was particular to nurses’ knowledge of individual patients.

[The patient states] ‘I'm tired,’ meaning he wants to go now. He [the patient] wants to go, meaning he’s had enough, right? When they [patients] say they're tired and then it [treatment] really isn’t doing anything. So you let them talk. I let them talk. (Chopin, auto unit)
Reluctance to Burst the Bubble of Hope

Nurses’ narratives revealed a sense of reluctance to “burst the bubble of hope.” When nurses felt a sense of knowing that symptoms signaled a patient’s impending death, they struggled with how to discuss their observations with the patients and their families. Sometimes patients or families directly asked nurses about a family member’s prognosis. These questions were uncomfortable for even the most experienced nurses, as patients and their families hoped for reassurance of recovery.

You want to be honest, but at the same time you don’t want to burst their [patients’/ families’] bubble because a lot of them have that much hope. They have that little ounce of hope. (Carrie, auto unit)

I don’t want to ask…I don’t like bringing up the if it doesn’t work stuff because I don’t want to dampen their [patients’/ families’] spirits and be like, ‘Oh my god it’s not going to work’…So I don’t want to be that person that gave that negative thought. So I just always like to reinforce if it does work…because they're hanging onto that something. And I just want to help them hang onto it. (Raylene, auto unit)

Nurses were reluctant to burst the bubble of hope because this notion was so closely tied to patients losing a will to live; a will nurses felt they played a role in helping patients to maintain when they felt challenged or discouraged. Nurses alone had to quickly judge each opportunity to talk with patients about the possibility of dying at the moment an opportunity arose. When appropriate moments arose, sometimes nurses were reluctant to acknowledge patients’ awareness of their possible dying, and hence talk about the threat of mortality.

I remember him [the patient] saying to me ‘I don't think I'm going to get out of here.’ I said, ‘I don't even want to hear you talk like that’ because I knew he could... he was strong. What he was going through, he had overcome the worst …I remember saying to him, ‘I don't even want to hear that. We're getting out of bed. You're going to do this [laughs]. You're going to do this. (Snook, allo unit)

In contrast, a few nurses expressed guilt for being less authentic or truthful around their sense of hope based on their knowledge of a patient’s state. On the one hand, they were expected to work alongside a life-saving team to help patients recover or promote the possibility of a prolonged life, yet had to recognize there were times when the reality was that lives were ending.
Nurses, such as Shania (below) recognized that they sometimes felt they were “sneaking around” the life-saving team to talk to patients or families about possibilities of patients’ imminent death.

Yeah, you do feel guilty you feel…You are sneaking around saying, ‘I'm going to tell you this but don’t tell Dr. X that I told you… (Shania, allo unit)

While other health professionals talked to patients/families about another study drug or attempting another bone marrow transplant, some nurses tried to validate patients’ existential suffering.

You can't say, ‘Oh no, you're going to…’ You just have to say, ‘I know it's really hard for you and I'm really sorry that it is like that.’ You can't use the word [die] or, if you could have changed things, because you don't even go there. You sympathize. (Anna, allo unit)

Nurses told me of regrettable or sad deaths. Sometimes they expressed guilt and anger about it, and at other times, they expressed grief over not being able to give patients the kind of dying experience for which they had hoped. Nurses expressed a desire to protect patients from meaningless suffering. This hope was one not to protect them from the threat of mortality or death, but from patients’ experiencing a loss of control and capacity to define the limits of their suffering, and to have meaning in their lives.

He lost everything. He was like a skeleton. You know a skeleton? There was nothing of him. He lost his dignity. He lost his mind, because, you know, the confusion with the drugs for pain relief, because it's a horrible thing to go through because it's one of the most painful things you can have when they have graft-versus-host. (Anna, allo unit)

Not very nice deaths, because of the chemicals, they [patients] had lost weight. They couldn’t eat. They lost their hair. It was the indignity of the whole thing. And I almost, many times, wanted to say, almost, expressed my anger. (Birdygirl, auto unit)

These narratives reflected nurses’ concern for patients’ suffering and basic dignity. Nurses sensed when patients were “lost in a void,” as Anna stated below. This knowledge was particularly distressing when a patient’s will to live was felt to be quietly “given up” or “lost” unnoticeably and irrevocably.

Their whole attitude, their whole personality changes. They're not the same guy you knew. They're different. You've lost them somewhere in a void and you can't get them back…The spirit has given up. So your soul has no desire, you can't. You see that in a lot
of these patients. Cancer patients, if they have given up their fight inside, then you cannot bring them back, no matter what, because their spirit is lost. It's all gone. There's nothing. It's a shell that is just living. (Anna, allo unit)

Yeah they would withdraw, especially…not even then, not even with a lot of complications, even on their day five, or day six which is the hard days for them, they would just withdraw totally. You could not even get anything from them. (Megan, auto unit)

The above narratives showed nurses’ acknowledgement of patients’ vulnerability to suffering a loss of meaning, connected to their will to command their lives. Nurses resisted acknowledging disruptions in the meanings of cure, but they were intuitively aware of patients’ vulnerability to existential distress, and suffering. The nature of nurses’ concern about maintaining hope versus bursting the bubble came to the forefront at several critical and temporal points of the patients’ journeys, before, during, and after treatment. On these units, while technology sustained lives, it also brought forward questions and concerns to the forefront for nurses about how to support and facilitate a sense of meaning in patients’ suffering and to preserve a will to live and support their dying as patients moved towards an end-of-life phase.

Whether to and How to Respond to Patients’ Distress and Dying

As nurses reported that patients did not openly express fears of their threat of mortality and dying, nurses feared initiating these conversations. Whether or not nurses did respond often depended on their emotional attunement to patients/families and their rapport with them. First, I discuss what influenced nurses to decide whether to respond to patients’ expressions. Next, I discuss how nurses responded.

The characteristics that influenced whether to respond to patients’ distress and dying depended on their emotional attunement to the patient’s fight with cancer versus preparing patients to let go. At any present moment, intents fluctuated depending on whether they had the
knowledge, skill, agency ("saw" possibilities), and whether they had the support and coaching of colleagues to properly respond to patients’ and their families’ distress.

*Emotional Attunement to Fight or to Let Go*

Physicians and families of patients had a tendency to reinforce meanings of cure, rather than acknowledge patients’ existential distress. For example, while most nurses were emotionally attuned to patients’ anxiety and hopelessness, they were compelled by the curative culture and often patients’ families attitudes, to continue aggressive treatment even when patients did not want more treatment.

On that first day, I remember when he saw I was going to hang the chemo, he said, ‘Anna, please don't hang it. Please don't, I beg you, beg you, don’t, don’t. I don't want to have this. I don't want the radiation. I don't want any of it. I want to go home.’ But Dr. X just spoke and his mother spoke and they said ‘Yes, you've got to have it.’ I just felt so wrong. (Anna, allo unit)

[Patient states] ‘Well, I get the chemo because they want me to have it,… but I'm tired.’ He kept saying that he was tired. He didn’t want any more, but the family keeps saying ‘Go for more. Go for more. Why don’t you go for more?’ (Chopin, auto unit)

In a similar manner, these narratives demonstrated the challenges faced by families and their difficulties in confronting or coping with limits of treatment. Some families were “upset” or “angry.” Some families recognized that treatment was not effective, but did not wish to share this openly with their loved ones (including the patient). Nurses worried about how families would react if informed of “the truth.” Though nurses resisted acknowledging the dying of patients who were facing impending death, this became the root of their concern about the patients’ and families’ distress.

Sometimes if the situations are...things that I can remember is if the family is not coping. The family is...lots of times families become angry because they're not coping and that makes it difficult. (Tess, allo unit)

I'm just thinking, ‘this is not good.’ He [the patient] was there a lot. He ended up being there a long time, and then he came back in and then he went up to palliative care. And when he came back, he and his...again, his wife was really upset…The wife was really,
really anxious, and not only do you have one patient but you have two patients, right? (Betty, allo unit)

Adding to challenges in preparing patients for the possibility of dying, were the ways patients themselves expressed their own sense of an encroaching end of life, as Snook stated,

They [patients] won't come out and say, ‘I think I'm dying.’ They'll say... and then you have to get clarification. I've come to the end of the road or whatever the euphemism. (Snook, allo unit)

Coming “to the end of the road,” was a path set by the boundaries of when recovery, cure, or symptom management was not realistically expected. Moving past these boundaries called upon nurses to trust their intuitive capacity to respond in order to restore hope and protect patients from unnecessary distress. The majority of nurses expressed a need for more knowledge, skill, and confidence about their communication and feared augmenting patients’ anxiety, and anger, which held risks of legal consequences.

I think it's just comfort in your profession and just...being confident, I think. I still, because...yeah...I'm not always confident in my existing skills. (Raylene, auto unit)

Also, it's a theme of confidence. If you go up to a family member or whatever and you're really confident in your approach—I find when you are communicating it, and you're saying, ‘This is what she needs.’ It's not a question about, maybe...there's no maybes here...We need to help her. We need to do this. This is not what you... Is this what you would want? And sometimes it's also almost a brutal truth, but you have to actually just put it out there for them to see. (Carrie, auto unit)

Once, I made a mistake and she [the patient] said ‘Am I dying?’ And I said, ‘Are you kidding, you’re a cat with nine lives.’... And I was so upset with that after....It was a great opportunity to say something, like, ‘Do you feel like you’re going to die?’ We could’ve opened up a little bit of...but I'm usually in such a hurry that I can’t open up a little bit of anything. Then I have to stand there and take what I get. So I do try, sometimes. (Birdygirl, auto unit)

**Situated Knowledge, Capacity, and Perceived Control to Fight or to Let Go**

Past, present, and anticipated knowledge of the disease process, combined with patients’ cues, augmented nurses’ ability to see possibilities and respond properly to patients’ and families’ distress and dying. While biomedical knowledge of cancer continually brought forth
further technological tests and aggressive treatment, situated knowledge of the patient brought forth conversations regarding treatment options in response to patients’ declining health.

Sometimes you do say hopefully it'll get better, even though you know that their white count isn't increasing. So sometimes you'll have a patient who's Day 12, whose white count is supposed to be higher. Or someone who has been here for 18 days and you know that their white count should be a lot higher, but yet it's not. And so you're just like uh-oh. (Raylene, auto unit)

We have a pretty clear idea from the lab values and everything else and the way the disease is going in discussion with the doctors, where it's actually going, that we need to start preparing them [to let go]. That we are no longer here in the continuum, but maybe here and we need to start doing the [end-of-life care] work. It just depends with the patient, right? So it depends if they have GVH [graft versus host disease] and the GVH is Grade Four. Well they don’t have long to live. That time is running pretty fast, so you have to have a good understanding of the disease process. (Kandy, auto and allo units)

Nurses’ narratives showed the varied ways in which their past experiences and expressed need for more continuing training and practice influenced their capacity to respond to patients’ distress and dying. In particular, they talked about their own feelings of this kind of work being stressful.

It can be draining, I guess. Because you're never really taught in nursing how to be with a dying family. (Julie, allo unit)

Sometimes, I'll ask them, ‘What's the next plan?’ [Patients respond] ‘Well I don't know.’ And so I do tell them, ‘There's some study drugs that you can go for but then also there's...you can spend a lot of time at home.’ And then that’s it. I don’t like to talk about the rest of the stuff because I really don’t know how to continue on with it. Sometimes I'm afraid for them, I don't know. (Raylene, auto unit)

I always regretted not going in. And I think he [the patient] died before the end of the shift, before I had a chance to go in. I've never heard from his wife again. I think maybe she came back to visit, but... I don't know. That was one of my saddest, or not my saddest.... well everything is sad. Sad is sad right? But it's something I always carry with me because I didn't take the time, then, to do it because of my own fears and because of my own feelings. (Shania, allo unit)

In some nurses’ narratives, personal characteristics of patients were brought to the forefront to help nurses make sense of treatment. Interpretations of signs and symptoms of fatigue, for instance, provided the knowing that dramatically altered nurses’ responses from one patient to another.
Because I know what the underlying reason is for him. He was just tired. He was exhausted. It had nothing to do with the fact that he was [about to die]... at that point he didn't have life-threatening injuries. What he had was a long case of recovery through exercise and all that stuff because his muscles were wasted from all the steroids. (Snook, allo unit)

I was talking to Dr. X because she's been sleeping a lot. And he was saying he thinks it's her way of withdrawing and to try to get the whole process over with really quickly. And I sort of think he's right, because it was totally different than the way she was the first time. Because she is my primary, I had her a lot. (Zhanna, allo unit)

Nurses expressed that characteristics of patients and/or their families were sometimes impediments to prognostic conversations with others (patients/families/health professionals). Nurses engaged various reasoning in talking about the threat of patients’ mortality based on the patient’s age, and a belief that dialogue about death was more harmful for younger than older patients. Additionally, there were language and cultural barriers associated with talking about death. These individual characteristics of patients and their families influenced whether it was appropriate to broach discussion of the threat of mortality and dying.

It's very individual. It also depends on what age they're at—how old are they. If you're talking to someone who has a language barrier, someone who's really old, someone who's sedated with drugs, you know, how far are you going to take this conversation, your day, that kind of stuff. (Carrie, auto unit)

Sometimes even when they're told that they're DNR and they're dying, some cultures will say ‘Well, we still want aggressive treatment.’ So to the end, they're getting ARC [Aids Related Complex] symptom control or they're getting antibiotics until the day they die. Because they still want aggressive treatment, even though they’re DNR patients. So it just depends. (Raylene, auto unit)

Nurses expressed challenges in knowing how to tell patients that they had reached the limits of biomedicine. A common way to do so was to tell patients that aggressive treatment was no longer a choice using phrases such as, “nothing else,” or “nothing more, could be done for him/her.”

The patient is very quiet, anyways, but the look about her is different. I think she knows, because she’s been told there's nothing else that we can do for you. (Potter, auto unit)
The phrase of “there’s nothing else we can do for you,” meant that patients were made aware of their boundary or limit situation and moved closer to death. In doing so, nurses expressed that patients’ suffering might be augmented, but similarly challenged them to restore potential meaning for their lives.

Sometimes patients were not ready to decide on what they wanted done during medical emergencies or they were not given proper information to assist them in their decision-making regarding a “Do Not Resuscitate (DNR)” order. In the narrative below, the nurse and doctor held conflicting clinical expectations that influenced nurses’ perceived control to talk about imminent death. At times, the health care team had conflicting perspectives of how to manage treatment or care at an end-of-life stage.

Yeah, so Dr. X comes in, he hates dealing with this, I know Dr. X really well. So he goes, ‘Okay fine.’ He [Dr. X] comes in and he pulls up a chair and he sits down. He points out to the man that he's got all these tumours and he said, ‘We can give you more chemo.’ I'm glaring at him [Dr. X], like, more chemo?! Don’t mention the word because we've got to make him a DNR. We can't be giving him hope. (Kandy, allo and auto units)

In the above narrative, the nurse intuitively sensed that the doctor did not want to discuss options for end-of-life care even if the life-saving team had reached the limits of biomedical treatment. Nurses experienced a dilemma as a result of encouraging patients to take extreme risks with their well-being, no matter what the consequences were. They also recognized that patients would opt for unrealistic treatments to maintain the smallest amount of hope for recovery or prolonged life and prevent them from cultivating moments patients could let go.

It was hard to care for her [the patient] some days, because she was getting frustrated too. But she wanted to go ahead with all these different options, I guess, that were given to her. (Julie, allo unit)

They're not asking any more questions. They're just going for whatever they can get. Because the doctor offered them 25% chance, and so they take every chance. (Chopin, auto unit)

The worst consequences to not addressing the limits of life-sustaining treatment occurred when nurses responded to life-threatening emergencies. Nurses’ responses were too often limited...
to direction from Do Not Resuscitate (DNR) orders written by doctors in the patients’ chart. Many patients, however, did not have a DNR order. Even when one existed, nurses told me that DNR orders were often not discussed with them or ignored. In the following stories, nurses expressed deep concern for a lack of preparation in responding to medical emergencies properly. In Shania’s story, her distress was triggered when a patient’s DNR order was ignored. The patient’s family not only witnessed his cardiac arrest but suffered meaninglessly when the medical team performed cardiac resuscitation and traumatized his body.

All of a sudden the fear [in his eyes], and I said to him, ‘John, I'm here.’ I think I just said ‘I'm here with you.’ And he had a hold of my hand, which I could just see, and that was it. And I felt so bad about that, because his wife and eventually his sister and mother showed up while this code was in progress. And I was upset with the doctor and you're yelling by this time, saying ‘He's a DNR!’ You know? They were sitting in the chairs in the service room, and all I could think of after they left, you know was, what a mess. (Shania, allo unit)

Nurses were particularly concerned when patients demonstrated that they knew time was running out and that recovery was unlikely. In nurses’ narrative about these situations, the possibility of imminent death was present and nurses were emotionally engaged in understanding and wanting to respond to patients’ distress.

Patients know. Patients can read a medical team's face... and family’s face. (Celine, allo unit)

I think that’s why she was afraid. They know. People know when they're going. And because she was such a strong lady, I think she hung on for a lot longer than someone else might have. (Potter, auto unit)

He knew he was dying, and he knew he wasn’t going to get out of here. And he was just very bitter about it. He sort of turned around and just wanted to go home. And then that was it. Shortly after that, he went home. (Zhanna, allo unit)

Nurses risked ridicule and disapproval when they advocated the extension of patients’ freedom to limit their suffering at the end of their lives. In these instances, the nurse attempted to foreground an emphasis with colleagues to prepare patients to let go. This conflict highlighted the influence of the curative culture above care that responded to the threat of patients’ mortality and imminent deaths.
Would our doctors ever say to somebody, ‘Would you like to go back at least to your home hospital so you can be near your family members?’ No, and if you approach them [doctors] about it, saying they [patients and families] just really need that support right now. [The doctor would say] ‘It's too far away.’ It's like ‘Oh, well they [staff of another hospital] couldn’t manage them at that hospital. They don’t have the know-how.’ And you'll say...and that’s when they think that you're being really smart alecky. (Shania, allo unit)

The curative culture did not draw upon ways that acknowledged its limits or about reaching its limits. As such, technology did not guide nurses’ care supporting patients’ distress during emergency medical treatment, nor did technology sustain hope in conversations beyond using technology or treatment.

I felt the patient didn’t get the care she needed…This [the emergency medical code] took, I think, over 40 minutes. As we were transferring her back to the ICU [Intensive Care Unit], she actually arrested on the way again. And luckily, she did come back…But I ended up leaving feeling, oh that was so bad. But if you’re not dealing with codes [emergency resuscitation] every now and then, you’re not used to it. (Carrie, auto unit)

As soon as it turned to be palliative, from full treatment to palliative, I didn’t really know what to do in there anymore. I'd walk in the room, and I'd think, ‘What do I do? I don’t have all these medications to give and I'm not so focused on giving him his blood counts and all that stuff.’ (Julie, allo unit)

Nurses responded to patients’ distress and dying in ways that reflected intents to simultaneously fight cancer while preparing patients to let go adherence to the norms of a curative culture. The four ways nurses responded were in responsive skills of involvement. These involved: communication about the threat of mortality and death, letting be and supporting families to let go, managing technology and technological intrusions to patients, and striving for easier deaths for patients.

**Responsive Skills of Involvement**

*Communication about the Threat of Mortality and Death*

The boundaries of the nurse-patient relationships were fluid and temporal; they changed with the connection nurses established with their patients each day. If the connection was

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considered “good,” then nurses were more apt to respond to cues from patients/families exploring meaningful goals beyond the expectation of recovery. Appropriate moments were when doctors or patients brought up questions about the risks of death, or when patients expressed an awareness of their mortality as they became visibly sicker.

Specific communication strategies that enabled nurses to acknowledge the threat of mortality and death were open-ended questions, summarizing patient’s statements, or asking questions that clarified meaning in their dialogues with patients.

I said, ‘You guys [the patient and family] need to think about what, like talk together, take time and talk about it [advance directives] now while you're well and stuff. What do you want done and stuff like that if you do get sick? Do you want to go to the ICU? Do you want to like?’...Stuff like that right...yeh...anyways. Sometimes I'm sure I've asked a patient ‘How do you feel about dying? (Tessa, allo unit)

When talk of the threat of patients’ mortality or patients’ end of life did come up, nurses reported that they responded to patients’ cues. Some nurses were unsure of what specific cues they were responding to, having simply felt “something,” Tess stated, but was unsure of what “it” was. Nurses described the following cues: crying, a sudden change in the patient’s personality or mood, patients expressing that they “had enough” of treatment. These cues acknowledged patients’ compelling threat of mortality and pushed nurses to move beyond life-saving technology.

Usually patients initiate it because it's something they need to talk about I think. There's usually I think a cue...Either they bring it up or there's something. (Tess, allo unit)

Yeah, a lot of the stuff I do is indirect. I'm not like, ‘Okay, we're going to talk about your feelings.’ It's more like when I go in there and I see what I see then I'll... that’s how they share their feelings. So if I see them crying, ‘You look upset. Why are you like that?’ So, like, with him, he was looking down and I'm, like, thinking about something. And if they do talk about ‘Oh, you know, I'm sick’ then I'll be like oh so what does that mean? And then I'll explore further. (Raylene, auto unit)

I mean if they said, ‘I'm not really…I didn’t really want to go through all this.’ So you just ask them, ‘What did you really want to do?’ And you just kind of explore their feelings really. Ask stuff that kind of leads to whatever they want. People usually would open up like that. (Megan, auto unit)
Additionally, some nurses provided cues that invited patients and their families to talk about dying and wishes for the patients’ end of life. If patients responded favourably, nurses invited them to continue talking with others about care at the end of their lives.

I think people give you...communicate so you can approach the topic. And if somebody doesn’t want to talk about it, they indicate that in some way. Either non-verbally, and you try to...You might try it again, and they say, ‘No I really don’t want to talk about that.’ That’s okay. But at least you know where they're coming from, in terms of doing it. But I think you need to approach the topic though, you know. (Kandy, allo and auto unit)

A few nurses mentioned the salience of informal coaching or mentoring to learn what to say or do when patients expressed existential distress or awareness of their dying. Coaches or informal mentors were other nurses with whom they had good rapport and who were open to questions.

She’s not like a very senior nurse but I'm like, ‘Hey, what do I do?’ And I can approach her and stuff because I have confidence in her ability. (Raylene, auto unit)

And the nurse that I was working with, who was so experienced, said to me, ‘Sometimes you have to tell them, even if they're not...’She wasn’t conscious. Even if they're unconscious, you have to say to them, ‘Talk about it with the family.’ And say to them, 'It's okay to die’...Now, I really appreciated that nurse. (Birdygirl, auto unit)

At this point, I wish to emphasize the importance of the patients’/ families’ fluctuating awareness of the threat of mortality and dying, which shaped nurses’ ability to talk about it. As such, timing talk of the threat of mortality and death was extremely important to notions of what was proper to do. One experienced nurse, named Kandy, explained in detail below,

It just depends on the person and the families, all of it comes together in terms of each family and what you know about them because you utilize all of the information in terms of when is the right time to do it. If it isn't the right time to...it's not the right time for every single patient. (Kandy, allo and auto unit)

The “right” time, according to Kandy, required that the clinical team’s awareness of imminent death, and willingness to talk about it, matched expectations of the patient and family.

I just pulled the husband aside and said, ‘You know, if you want any of this to stop and you don’t want her to keep going, you should talk to him [the doctor] now. Because you have to tell us everything,...So I said, ‘Tomorrow, pull the doctor aside.’ And I said, ‘You better tell him whether you want it to keep going or whether you want it to stop.’
And in the end, he told him that he wanted to stop all aggressive treatment. Which I sort of figured he would. (Zhanna, allo unit)

Surprisingly, nurses sometimes did not commit more of their energy to one course of action towards fighting for life or preparing patients for the possibility of letting go, even when there was compelling evidence of the patient dying. To some extent, my observations revealed reasoned or intuitive knowledge of their actions with patients. For instance, many nurses attributed a belief in miracles to justify their continued fight against cancer. Indeed, an important contingency were nurses’ experiences of patients mysteriously recovering. In those narratives, patients who were dying, and expected to die, recovered and left hospital. These narratives were highly valued by nurses and reinforced the belief in potential miracles. Nurses considered the event of death within statistical odds. But when miracles defied the odds, they brought forth meaning to patients’ suffering. Not only did miracles reinforce the power of life-saving technology, but it enhanced existential beliefs in the capacity of the human spirit to control their time of death.

If there is like a glimmer...because they have had people go to the edge and I've seen it, subsequently. I've seen it, people go right to the edge...and you think that's it, and they start to come back again, and they go home, and we go, ‘Wow!’ (Snook, allo unit)

At least three months, and he was doing so, so badly, from the first round. He got so depressed, I'd say for at least a month now, before we started anything on him for the depression and we finally started something on him and he's like a whole different person. He goes, ‘By the end of April, I'm going to be up and doing all my own care by myself.’ And I go in and saw him the other day. And honest to god you'd think it was a different person. He used to lie in bed, not doing anything. You'd have to do all his care for him, everything. You'd have to force him to do mouth washes. Now he's up and having his own showers. (Zhanna, allo unit)

No, but he had acute GVH [graft versus host] disease, started solumedrol right away and the next day, his acute GVH is gone. It's a miracle...Extra power from his wife. (Celine, allo unit)

In considering how patients died, I concluded that nurses intuitively switched to more emphasis on a concern to let go, in language such as, “It became pretty obvious to us…things weren’t going to get any better.” In other words, the compelling pervasiveness in nurses’
narratives to “let be and let go” was intended to protect patients from avoidable suffering by preparing them for the end of life, often not realizable on these units until patients were at the precipice of death.

*Letting Be and Supporting Families to Let Go*

Letting be the dying process and preventing families’ further suffering provided nurses an alternative way of being, a way that was not technological. These activities did not “fix” the patient’s body, but were elicited by cues from patients. Nurses knew that patients’ relinquished some part of their freedom when they were admitted to hospital (i.e., confined to wearing hospital attire, eating prescribed foods, and taking prescribed medications, while living in unfamiliar surroundings). Hence, nurses assisted patients to regain familiar ways of being. For example, I noticed a patient using a hospital computer to check his email. Another patient was wearing some of her own clothes under her hospital gown. Many patients had decorated their rooms with familiar items from their homes.

The involvement between nurses and patients was conveyed through the skills of simply being present and listening. These ways of being were intuitive. Experiences had taught the nurses about the finiteness of life and to appreciate the present moments in being accessible, available, and in conveying understanding and support.

We generally have time. Questions like this will come up when you have the time,... If patients feel like they can talk to you, you know, they’ve opened up and you have the time—extra time to just sit beside their bed side or just talk and say, ‘How you doing?’ Whatever. ‘You look kind of down today.’ Or, ‘You're happier today.’ Or whatever. Then they’ll sit and talk and say, ‘You know what I'm really worried. Today I'm not doing well.’ (Carrie, auto unit)

I mean you just let them mourn, mourn it through. And when they're finished, they'll get up and go. You don't try to stop them because they have to get if off their chest. (Anna, allo unit)
Nurses used regular and continuous contact with patients to monitor their distress and the progression of death. The act of monitoring directed strategies to preserve patients’ bodily comfort and deter their isolation. If the patient was unconscious, nurses were still able to pass on information to the family that allowed them to prepare for the patient’s death. Nurses were present and provided opportunities for families to be present at the moment patients died.

Those questions started coming out in the end...So we kind of had to do a lot of education...I said, ‘You guys are still her family. You guys are still the ones to make the decisions for her, but I just have, I need to give you the education surrounding what decisions you’re making.’ So I guess when they realized that, she wasn’t going to wake up and talk to them. (Zoey, allo unit)

So I told the husband, who was there, I said, ‘Her respirations have changed. Keep an eye on her. I think we’re taking a turn here.’ But I think she lasted another week, almost just slowly… (Potter, auto unit)

After patients lost consciousness, their families became more of the focus of care. Nurses’ intentions were to coach families to let be the process of dying and let go of the patient to move towards closure and some resolution. Nurses coached families in doing things that meaningfully connected them to patients and validated their grief. They directed families to help find meaning from their suffering. This kind of care often simply meant that nurses provided some comfort and made a difference to families during one of the most difficult times in their lives.

I encourage family to do whatever they want to. [The nurse tells families] ‘You want to help turn them, okay. You don’t want to help turn them? That’s okay too.’ Let them do whatever they want to do. And again, you get them a plate of tea and crackers and juice. You bring it in. You give it to them. And you let them know where the chapel is. You let them know you can have this room right here. Even just bringing them a box of Kleenex gives them permission to cry. (Betty, allo unit)

And it was just that...from where we [the nurses] had started, what we had heard and where he [the patient’s husband] had reached. I ended up feeling... leaving the floor feeling, that, you know what, I had made a difference. She had gotten better pain control, not behind his [the patient’s husband] back, but with him knowing. He had, I think moved to the next level, which was okay. I know where she [the patient] is. Maybe this is what she needs. And then those are the days that you just feel... go home feeling, you know, wow! (Carrie, auto unit)
When patients were unconscious, nurses took care of each patient’s body in meaningful ways nurses knew *this* particular person. The patient’s capacity to remain connected with their families through their potential capacity to hear became significant for what nurses hoped would occur. Nurses guided families to talk with patients in ways that maintained their personal dignity and connections with them. The patient’s energy was no longer directed to speaking and acting upon the world, but to *letting be*. In this way, nurses gave meaning to family’s experiences.

And I think it’s important too to tell them, ‘It doesn’t mean that she can’t hear you. It doesn’t mean that she doesn’t know that you’re here. It just means that she’s not going to be able to talk to you.’ So giving them the opportunity to talk to her and to say goodbye and to do these things, and let them know she can still hear you. Because that’s what I believe, and I share that with them. I think that was really helpful to them as well. (Zoey, allo unit)

We do talk about the hearing. How hearing's usually the last sense to go. And it's okay if they don’t want to eat, because usually, I feel a lot of families that’s... They're very focused on eating. I think they associate eating with being alive, I guess. And so, when somebody starts, ‘I'm not hungry, I don’t want to eat,’ they realize, ‘Oh, no they're not eating.’ So I think when somebody's ready to die, we just say ‘You know what, it's okay that they don’t want to eat. They're saving their energy for their breathing and being able to just be comfortable and listen to you.’ (Julie- allo unit)

Nurses empathized with families’ suffering and often tried to alleviate families’ anxiety if they could. The nurse, Betty, routinely tried to avoid having families witness the period when patients exhibited, she stated, the “death rattle.” (i.e., A gurgling sound sometimes made in the throat of a dying person, caused by loss of the cough reflex and mucous accumulating.) Another nurse, named Samantha, increased the amount of morphine to ease a patient’s suffering during her dying. This technical knowledge allowed the patient a more peaceful, and comfortable death in the presence of her family.

Instead of suctioning the patient, you just put a little atropine…Get atropine ordered. It dries up the secretions, but it [the “death rattle”] is very, very difficult to listen to for 24 hours a day if you’re in that room with your loved one…The family has to watch that. That’s hard. (Betty, allo unit)

Yeah, he [the patient] was still...not making any sense. So he could be in pain, or he could be just confused. So we started a morphine drip on him, just to make sure that he keeps comfortable. Then, because the family didn’t want to watch him suffer, they asked
us to increase the dosage. But the thing is, to increase that, I would have to follow the orders…One last time, I went into the room and just increased it, before the time was up and then the wife just gave me a big hug and said, ‘Thank you so much.’ Because that’s what they wanted, to have it increased. They really didn’t want to wait for another two hours before we increased the rate. (Samantha, auto unit)

In a contrasting case, when the nurse was unable to relieve the patient’s physical symptoms, this exacerbated the family’s distress and the nurse’s. Nurses experienced helplessness when they felt the patient to be inordinately suffering and felt there was little they could do. In those moments, there were no words to articulate the loss of purpose that the nurse, who recounted the following narrative, embodied.

The agitation in this lady was...like the pain that you could see that she was in was incredible. It was probably the most hard to see type of situation. The family was a big support. They were there constantly. But at the same time, with the family there watching on all the time when she’s in this pain and nothing you seem to be doing is working and they’re all looking at you like, ‘What are you doing? What are you doing?’ She would just writhe in the bed and she had some encephalitis in her brain, so she was showing like brain injury-type symptoms. Like her body was flexing, she was all... she was doing almost the fetal position motions and things like that. It was very hard to see. (Zoey, allo unit)

Managing Technology and Preventing Technological Intrusions to Patients

Caring for patients’ bodies held meanings for nurses about the end of patients’ lives. While the units invested a large amount of resources in life-saving technology, there were also mechanical devices to lift and move patients. There were permanent lifts in two patient rooms on the allo unit and a portable device on the auto unit. I observed that health care aides, known as “sitters,” to the nurses, sat by patients to prevent them falling from their beds, or to provide a presence to alleviate the patient’s distress.

Interestingly, when more resources were mobilized to preserve patients’ physical integrity, this provided a cue that patients were approaching the end of their lives. For example, placing patients on air mattresses to prevent pressure sores, or using a urinary catheter to forgo
the need for patients to lift themselves onto a bedpan, indicated that their bodies were, as

Samantha stated, “shutting off,” like the “lights in a house.”

So when I met her, she was bedridden and she was on one of those air mattresses that we
ordered from the outside. Which a lot of the nurses on the floor would say, as soon as
they get on the air mattress, it’s a quick decline down, because it means that they’re not
positioning themselves, they’re not moving. (Zoey, allo unit)

That’s right, and then that’s one sign that they're going downhill, and also, say for us,
sometimes breathing and urine output is quite a good sign to tell as well. Just basically
organs are shutting down. Just like if you think of the person as a house, and then you're
turning off the lights. In every room one by one, gradually all the lights are out and then
the house becomes dark. (Samantha, auto unit)

Technology and human resources enabled maintenance of patients’ bodily integrity up
until the moment of death. Contrast cases revealed nurses’ concern for the intrusion of
technology when the patient faced imminent death. In example below, Carrie stated that the
medical emergency was handled “badly” when the health care team “lost sight” of the patient’s
psychosocial distress and focused their attention on the person’s physical body. In these kinds of
contrast cases, nurses expressed shame and embarrassment for themselves, the patients, and
family members who witnessed the events.

So we [the nurses] talked about it. We talked, but I ended up leaving and going home
feeling it was a really bad code. It was really... It ran really poorly. I feel bad for the
patient. I felt bad for the way I handled things. I felt bad the way we sort of left things,
even for the staff, even for the girl that I was orientating. She had no idea. (Carrie, auto
unit)

In moving towards and accepting end of life care, the nursing care of participants became
less technological or biomedical, and geared towards interventions that enhanced quality of life.
Interventions, such as opportunities to enjoy hobbies or activities such as music, or a soothing
bath took into consideration the patients’ distress for the threat of their mortality. This nursing
care facilitated a sense of being and living moment to moment and gave pleasure or provided
meaning in patients’ remaining lives while on the unit. As such, nurses’ work was temporal and
dynamic, aiming to alleviate distress in present moments of being.
I'm going to say make them feel better for that time being...and giving them the whatever, to help them out or if they're looking forward to their husband coming in, then I'm like, okay, let's look pretty for your husband, then, let's shower, and I get them to shower and stuff. (Raylene, auto unit)

I went in and I said “What do you want to do today? What are your priorities and your care today?” And he just said, ‘Oh, I wouldn’t mind being clean, having a bath.’ So every day we kind of had a routine where I would give him this bed bath, but we'd put on this music that he liked and we'd do the bed bath. And we'd talk and he would help out when he could and it was just different, and it was okay. And I was just keeping him clean and comfortable, managing his pain. (Julie, allo unit)

Striving for Patients to Have Easier Deaths

The nurses associated an “easier death” with patients’ comfort, supporting patients’ capacity to find meaning in their suffering, to express a readiness to die, and to choose the way in which they might die. An easier death also meant that family remained involved till the patient took his/her last breath. Nurses told me how their involvement provided patients comfort. Acts of comfort were described as *more than* tasks that cared for the physical being of patients, but to care that maintained the integrity of patients as people, and preserved patients’ sense of their integrity and wholeness. This sense did not come from life-saving technology, but was created by both the nurses and patients addressing an urgent need that they shared: to remain emotionally connected to each other.

I went in and I sat there for a while and we were talking and I said what would you like to do? And I held her hand and she said ‘You know I'd like to...’and she was pointing towards the tape, music, and I said, ‘You'd like to listen to some music?’ And her mom said ‘I’ve had the music on all day, you know.’ And I said, ‘Well what can we do?’ So I was thinking, what can I do? What can I do? What can I do? And I thought, I'm going to sing for her. (Carrie, auto unit)

All the nurses are very, very kind, we all...even though they appear to be unconscious. You talk to them, you stroke them, you push their hair back. I mean, it's not just the physical care. You bathe them, and you put on a clean Johnny gown and comb their hair and that sort of thing. There's that touchy-feely, strokey thing. Do you do it for them or do you do it for yourself? I don't know. Sometimes...I mean, I've cried with patients. I've cried with patients’ families, you know...not breaking down sobbing, but you're doing your thing and you've got tears in your eyes. (Shania, allo unit)
I considered that meanings given to transcending suffering did not necessarily involve religious practices, but reinforced personal ways of remaining connected to a greater, shared purpose. As such, activities to honour patients’ and families’ spiritual beliefs gave meaning to patients’ and families’ suffering and gave nurses opportunities to experience meaningful involvement.

They were a Muslim family. So there was a lot of things that they got the chance to do as part of their faith. Because they were willing to accept that this person was dying as opposed to if it was fight, fight, fight. And she just died and if they didn’t expect it, they wouldn’t have the opportunity to prepare...There were certain things that they needed to do to prepare her for death and things like that, which they got the opportunity to do. (Zoey, allo unit)

When she was leaving, we all just went around her [repeats this] and said goodbye. We were sad, because we knew we were saying goodbye. We knew where she was going. But she was, like, ‘I'm going to...we'll party in Heaven,’ you know, saying things like that. ‘We'll have a party when you guys come and join me. (Julie, allo unit)

Although nurses did not necessarily understand the meaning of the families’ religious acts, they valued being involved in that part of the patients’ care. Many nurses were open to spiritual rituals and they appeared to feel privileged to be a part of them.

Because not really knowing the religion very well, but knowing that probably was something that they would need to do, even broaching that. They actually involved me in some of the things that they needed to do because there was things like shaving and things like that, that they needed assistance with. (Zoey, allo unit)

Nurses’ sense of meaningful activity nurtured their felt responsibility meant to comfort families’ and validate their grief, as well as restore a sense of control in the process.

There's nothing much you can say. But you just spend some time with them in the room and watching things. And they understand. They know you're there for them. You come and check their child, make sure they're comfortable and stuff. And they help you wash them and they help to take care of them. They help you change their diapers. They feel they're doing something, their involved...They feel totally involved then, and they’re okay. (Anna, allo unit)

Nurses attempted to give patients and families the things they needed at the moment they needed it, whether it was information, privacy, comfort, or a cup of tea. Many offers of
Nurses expressed a need to clarify and advocate for patients’ wishes at the end of their lives.

We [nurses] told the doctor. We said, ‘I don't know why you would've told them [the family] [that the patient had] a couple weeks, because we can see.’ But because we've seen him daily, and through the day, you can see the deterioration, and you know, compared to yesterday what's different. (Julie, allo unit)

I went and told Dr. X, I said, ‘He doesn't want this treatment. You've got to think about it because he's refusing. He's been telling me this all along.’ (Ann, allo unit)

Although nurses talked about advance directives and treatment options as a prescribed way to enter into conversations about the end of life, it also opened up opportunities to discuss ways to preserve patients’ control and capacity to explore meanings of their suffering.

Yeah, she couldn't talk, she wrote down...After he [the doctor] left the room, she [the patient] said, ‘There's no treatments left for you.’ She wrote down on the board, ‘I want to go home now!’ That’s what she wrote. I called him [the doctor] when everybody was here. They all go in, and they decide that she's going to try palliative care. The Palliative Care team comes two or three hours later. This is all one day, yesterday, and they say, ‘Okay, she's a candidate and it looks like the way that her white count is growing. She's got maybe a week, if, if. (Birdygirl, auto unit)

Nurses enabled patients to voice their will near the end of their lives. Once it was voiced, nurses coached patients in altering their futures, whether in hospital or in going home.

We transfused her with platelets and transfused her with blood cells. She was bleeding all the time. But anyway, she said to me ‘I think I'm dying.’ [I said] ‘How do you feel about that?’ She goes ‘Well I don't want to die here.’ I said ‘Well you know you can go home. They'll set everything up for you.’ She goes ‘Are you sure?’ And I said ‘Yeah. Yup. They'll send a bed if necessary.’ She didn't last that long, but she did go home and she did die at home. I feel good about that one, that's for sure. (Snook, allo unit)
Some of the patients I've had have inspired me because they’ve been so gracious with it and have made these decisions. They're able to say, ‘These are what I want. This is the type of death that I want,’ and I see that we can provide that for them and that it's possible to have a death that you would like, that that’s how you would want to go. (Julie, allo unit)

Nurses expressed that easier deaths preserved opportunity for the patient/family to prepare for where patients might die and acknowledgement (to some degree) of their dying. The “natural” time of death was when patients expressed readiness and acceptance of death (nonverbally or verbally).

She said, ‘I don’t want to give any more. I'm ready to say goodbye.’ It was emotional, for her, so we talked and I said, ‘That's fine, if you're ready.’ And she was grateful that I gave her that option, to settle and just come to those terms. (Julie, allo unit)

Carrie talked about how patients mysteriously awoke from a state of unconsciousness to say goodbye or to resolve any last concerns just prior to death.

It can last for a day, or even like part of the morning, part of the afternoon. They just do a quick perk-up and we generally will refer to that...this is maybe her perk before she died or this might be a perk before he goes or whatever. And we generally refer to it like that. That might be total coincidence or it could be a myth, but it's funny that we see so [many]...And it's not just me. I think a lot of the nurses—we refer to it, you know, like...and there might be a better sort of terminology for it but we just call it, the perk. (Carrie, auto unit)

Nurses, such as Zoey and Birdygirl, often told of patients “waiting” for someone to provide them with permission to die. This someone was usually identified as a family member or a friend. Nurses described how patients waited for who they wanted present at the moment of death, if indeed they wanted anyone there.

So then I said to him[the family member], ‘What I need...She's [the patient] very comfortable now. Yesterday she was very agitated.’ So I said to him, ‘One of the things I'd like you to do now is to go in and give Colleen permission to die.’ (Zoey, allo unit)

She kept hanging on, hanging on, hanging on. And the nurse that I was working with, who was so experienced, said to me, ‘Sometimes you have to tell them. Even if they're not...’ She wasn’t conscious. Even if they're [dying patient] unconscious, you have to say to them, talk about it with the family and say to them 'It's okay to die.’ (Birdygirl, auto unit)
Nurses were also concerned about individual patients’ wishes to choose their place of death. Nurses of the two BMT units accommodated patients who wanted to die there, but also advocated for patients who wanted to die at home. They did not judge one place (e.g., home, palliative care unit, BMT unit, intensive care unit) the best place to die. Instead, they recognized the hopes and resources of each patient’s family and whether the family’s community could support that particular patient to die in the manner and place he/she wanted.

Often, in my cases, it's not so much about what the dying experience is going to be, it's more…Where is it going to happen? When is it going to happen? (Shania, allo unit)

She wants to go home to die, so I'm making this happen. I don’t care who I have to…I just wanted her to be home and we [the nurses] got her home. But it is a very... like you said, we're, the nurses are fully the caregivers, throughout that whole palliative process. (Julie, allo unit)

The room right across from the intensive care unit, the hallway attaching us is the first room that’s a private room. So we can extubate him, rush him over, and put him into bed, and he could die at [name of institution] with us. And he [the family member] said ‘Oh I didn’t know you had all the equipment and stuff to keep him on a ventilator,’ I [the nurse] said ‘No, we don’t. But if this is his choice, and you would like him to be with people that he knows, and to die with us, we're willing to take him, and to create the bed there. (Kandy, allo and auto units)

When the family could not be present at the moment of a patient’s death, nurses were usually there. Nurses reassured the family that the patient’s death was comfortable and peaceful, and that he/she was not alone. Nurses’ emphasis on their connection to patients/families was infused in their language used in narratives about the moments patients died.

I just stayed with him until he took his last breath. Because I just felt, I'd never let anybody die alone. (Julie, allo unit)

So I said to her, ‘You must have lots of questions. You must have at least two questions.’ Okay so what two questions? ‘Did he die peacefully? Did he die on his own? Right?’ I said to her, ‘You must want to know if he died peacefully or was he in pain or that…Did he have somebody around him when he died? So the first one, ‘Yes he died peacefully and he was not in pain.’ And I said, ‘There were three of us.’ I said, ‘The chaplain was there, the student was there,…and I was there. So we were with him all this time so he did not die on his own. (Chopin, auto unit)
Some nurses expressed a preference to be with patients and families at the moments patients died for their own sense of closure and peace of mind. Zhanna and Potter expressed that a patient’s death gave them a sense of “resolution.” Death provided an opportunity to reflect on the nurse’s decisions and connection to the patient in ways not limited to decisions in performing life-saving tasks.

But I mean you want to be there for them anyway. I'd almost prefer for people I like, and I get along with—I'd almost prefer to be there, because then you can be there for the family. Because, a lot of times when they pass away, families say their last goodbyes and then they leave. So if you aren't there, you're not going to be able to console him[the spouse]. You're not going to be able to say goodbye to them[the rest of the family], either. (Zhanna, allo unit)

Should she pass, I want to be here. Not even if I'm her nurse working with her that day, but just to come full circle. I need to know that she’s passed. And sure enough, I was about to go on vacation. I came in the shift before I left, and she had died the previous day. That felt good, everything’s done. I can close this part of my work life. (Potter, auto unit)

In summary, whether and how to respond to patients’ distress and dying required a complex skill of involvement including emotional attunement to patients’ fight, situated knowledge, capacity, and perceived control to respond. The growing possibility of patients’ imminent death required nurses to gain a clinical grasp of the patients’ situation and trust their ethical judgment to respond in the appropriate way. If nurses had responsive relationships, they could communicate about the threat of mortality and death, let be and support families to let go, manage technology and prevent technological intrusions to support patients’ comfort, and strive for patients to have easier deaths.

Coping with Patient Involvement

*Patient involvement* refers to the nurses’ therapeutic engagement with patients. The nurse-patient relationship involves not only a professional but personal investment, which shapes its emotional nature (Benner, et al., 1996). While nurses expressed that their involvement with
patients was very rewarding, they expressed sadness and suffering when patients were told bad news in their fight against cancer.

We’d seen him through kind of good and bad—when he was doing better or when he got worse. For me personally, it's funny right, because you develop such an attachment. I remember one time, I think the doctor came in and told him good news and all of us around the bed [we’re] like, crying or like teary-eyed. You just develop…like you're so happy that they're doing well or it's so sad.. to see them suffering. (Tess, allo unit)

The characteristics that described this sub-theme were: acknowledging the threat of nurses’ mortality, tempering patient involvement, and releasing tensions created by their conflicting concerns.

Acknowledging the Threat of One’s own (Nurse’s) Mortality

Nurses became increasingly aware of their own mortality, potential for losses in life of loved ones and experienced themselves an “existential threat” in their work.

I just…you know, you look at these people and you think this could be me. I'm 45, it could be me. It could be my daughter. It could be my husband. It could be my mother. (Betty, allo unit)

Surprisingly, the nurses who discussed their own vulnerability to dying in a similar way felt conflicted about whether they would undergo a BMT treatment. These responses may have been a way of maintaining some personal distance from patients’ experiences. Talk of death required self-awareness (i.e., reflexivity) and reflection about one’s own felt responsibility to control and create suffering from a similar disease or treatment-related side effects.

Knowing what I know, I’m not in the position where I’d have to make that decision, but I ask myself all the time, ‘What would I have decided if I had been this person and knew what I knew now, would I have gone through with this?…A lot of times it’s no. (Zhanna, allo unit)

Anybody that’s worked up here all say, they're not having a transplant. I mean, there's the standing joke that if you get the diagnosis, you go out and max out all your credit cards and don’t have to worry about paying it back. (Shania, allo unit)
Collegial support was critical in enabling nurses to acknowledge their own threat of mortality. Nursing colleagues provided awareness and communication tools beyond those of life-saving technology. Additionally, they provided a resource for support and learning how to cope with death. Addressing nurses’ distress evoked by patients was common in conversation amongst nurses in the staff conference room or in the nursing station.

I don’t think that you are able to do that [experience patients’ suffering] if somebody then doesn’t help you deal with the suffering and make sense of it and come to terms with it. It's a very painful thing to have to go through on a regular basis, and to put it in perspective. So I don't know that we can expect that of people [nurses] on an ongoing basis and to never see that the suffering ends. (Kandy, auto and allo units)

Someone is always there to listen to you that understands, because they know the patients, they know the population. They've been in the situation like that themselves before…You just find your places to say, ‘This is what’s going on, what can I do? (Zoey, allo unit)

For many nurses, the idea that they were susceptible to the same suffering as patients brought meaning to their everyday experiences in the present. The most rewarding experiences they revealed were not technically being able to save a patient’s life or manage a patient’s pain, but being involved with the idea that patients and they lived more in present moments of life.

I think so, too. I think for...I can't speak for other people, but for me, I just find that I don’t sweat the small stuff anymore, and it's just...You look at things differently. Because I used to think, you know what, I will always have a good time after I retire, or if I do this. It was more future oriented. But now I'm more present, living in the present. (Samantha, auto unit)

In acknowledging their own potential threat of mortality, nurses expressed that their work weighed heavily on them, and they needed help to understand and cope with it.

Tempering Patient Involvement

Participating nurses attempted to temper the tension inherent in the conflict between fighting cancer and preparing for the possibility of letting go. Nurses’ involvement was not based on concerns that patients might die, in as much as they were concerned about patients’ suffering
having meaning and the presence of a quality of life until the end of their lives. When nurses expressed satisfaction in alleviating patients’ suffering as much as possible, it permitted them to maintain personal boundaries between their personal and professional selves.

I’m able to sleep at night because I know I’ve done everything possible to make my patients’ day the best at the moment. (Potter, auto unit)

As a nurse, doing the best you can. Life work as a nurse I think in any job…as a nurse…in any unit…is a challenge. You do not know what you’re going to face today. But you just come in and you do the best you can. You do it and then you go home. (Anna, auto unit).

Nurses’ coping with patient involvement was unique to the particular patient and their family. Nurses formed connections that were empathic and searched for similar characteristics, life patterns or goals that would assist in forming bonds; the connections were dynamic and reflected ways that nurses had been involved in other relationships, with friends and family. Often, connections with patients mirrored relationships with others, like themselves, or with people they knew.

He's 62, the same age as my dad. And I'm just, like, ‘Oh my god, this could be my dad.’ So I treat him like I would my dad. I'd be like, ‘So, we slept well last night?’ Tickle his feet, you know, to wake him up and just talk to him like that. That’s the first thing that came to my mind, he looks like my dad. This young girl here, she's my age, so I interact with her the same way I would with my friends. (Raylene, auto unit)

Nurses coped with their emotional connections with patients by tempering their involvement with patients. This meant that they balanced their personal and professional involvement. Acting professionally meant not showing intense emotions in front of patients and their families. Through this behaviour nurses maintained a professional distance—not an actual physical distance or lack of empathy for patients, but a felt responsibility that allowed them to tolerate the threat of patients’ mortality and the many deaths they experienced, sometimes in one day.

I found out I got burnt out. I got really too emotional, because you get to know these people so well…I think it wasn't balanced enough for me initially. I didn't have a proper understanding of the balance. Emotionally, it was really wearing on me. I think, as the
years have gone along, I've learnt to balance, to get to know your patients but also have a bit of a distance with your patients...You need a balance. You need to be able to separate a relationship and a nurse-patient relationship...Because we see many deaths. If you don't have that balance, then I don't think I would have lasted...It's like a distancing thing you do in your head or something or maybe in your heart or something...There's kind of a line that you learn to not cross. (Tess, allo unit)

Many of the nurses spoke about coping with patient involvement by balancing their work and other life pursuits. Work-life “balance” was the key to surviving the experience of so many patients’ deaths. The balance varied each day for each individual. Seasoned nurses reported that novice nurses were at risk of becoming “unbalanced” with the emotional burden of work. Yet it was only by recognizing a loss of balance that nurses recognized how they had learned this balancing skill.

In your balance, you've got to get it right. Otherwise, you are going to really burn out emotionally, mentally. Physically, of course, you're totally burned out anyway. The other balance, you've got to get it right and if you have, then you can survive it and you can be a better person with those patients. (Anna, allo unit)

For nurses coming in, I think that it's just important to create some sort of a balance so that you don't get burnt out. But I kind of think that you learn that as you go. You kind of learn that as you go. It's hard to say make sure you keep a balance as you start. (Tessa, allo unit)

Some nurses, such as Zhanna, spoke about ways to “push aside” the emotional burden. The doors of the unit and hospital concretely limited how far they carried their emotional burdens. The doors provided a symbolic exit, from which nurses could temporarily escape tensions of their work and contain their emotions. Putting aside emotions also meant compartmentalizing them, to avoid them contaminating other parts of nurses’ selves.

I'm the kind of person that I come to work and I do my work, and I go home, and I'm away from work. I don't really think about work a lot when I go home. Work is one part of my life and then I enjoy the other parts of my life, which I think is good because I'm not thinking...I don't even really like talking, like, when you meet nurses and everyone wants to talk nursing. I'm like...oh, I'm not at work right now. I think that's good because I go out and I just do things that I really enjoy. It's a break from your mind, and then you come in here and you're refreshed and ready to go again. (Tessa, allo unit)

I guess you've got the ability to switch off as you walk out of this place. You learn. You don't take your work home. Of course, there are things that will affect you, like a child, a
young person, a situation. But you learn to switch off, because that's the most important thing. If you carry things home, and you keep worrying at home about this, that, and the other, and keep all the time work, work. It'll destroy you. You just switch off. Once I walk out of this door, that's it. It's finished. (Anna, allo unit)

Some nurses expressed that their existential beliefs gave them strength to tolerate the conflicting concerns and uncertainty in their work. Acknowledging the uncertainty of patients’ futures, while stressful, provided some measure of relief and comfort through faith of what lay beyond the limits of life-saving technology. Reaching these limits meant taking a leap of faith, and trusting other ways patients were connected to significant others, or to a higher power in the world.

And sometimes, with some patients, they’ll come up and say to you, ‘Do you think I'm going to die?’ Or ‘How long do you think I have?’ Another favourite thing I find the patients ask you, ‘How long do you think I have?’ or ‘In your experience, how long?’ You say, I can't answer that. Even God can't answer that, right? I can't answer that. It's like, ‘Nobody can tell you, even the doctors can't tell you that.’ (Carrie, auto unit)

And I could say, ‘I really don’t know.’ Sometimes I have said that I can't get a sense of what to tell you. ‘I know about cases, when every case is so individual, and you're very individual.’ They would take that. A lot of people take that, they like that. (Birdygirl, auto unit)

Tempering the personal and professional involvement through balancing their intimacy and distance from their own distressing emotions was sometimes overwhelming. In some narratives, participating nurses told me how they avoided responding to patients’ distress or detached from their patient involvement to protect themselves.

**Avoiding or Detaching Self from Patient Involvement**

Even though nurses mastered life-sustaining skills, they sometimes sensed the futility of their goal to manage symptoms, futility based on trying to alleviate patients’ despair, immutable by medical treatment.

You know, it’s frustrating, it’s frustrating, because you can’t seem to get ahead of the game when somebody’s in for that long. He’s [the patient’s] very draining to look after because of all the emotional support. And it’s hard for a nurse to hear someone yelling and screaming in the room and just stand outside and not go in, because that seems to be... It’s worse when somebody’s in the room, so sometimes you just have to stand back
and leave. And here, you’re normally a nurturing, you want to get rid of the pain, you want to make them better. Where in this situation, it’s not necessarily anything that we can make better. So it’s frustrating. (Zoey, allo unit)

Some nurses attempted to silence or avoid the expression of their distress when they became upset on the unit. They silently experienced shame or anticipated criticism for disrupting the culture of cure and diminishing their own responsibility as one saving or sustaining lives. In the narratives below, nurses shared a mutual pretense and talked about how they avoided or withdrew from talking about the threat of patients’ mortality or imminent death.

It was hard back then, ten or 20 years ago…It was much harder then—still is hard…There’s a lot of diarrhea and a lot of illness. I mean, it’s really not a beautiful sight. I didn’t ever say anything because I thought they [the doctors] must know better than me, right? And I’m just beginning this, so I’m going to keep my mouth shut. (Birdygirl, auto unit)

Sometimes if something happened on the floor, and I find myself at the point where I'm going to cry, I'll just leave the area and go somewhere else, or I won't say anything. (Julia, auto unit)

Nurses reported not having the confidence to attend to patients’ distress, a concern often not recognized or valued by the culture of cure, nor even sometimes by nurses themselves.

Yeah, well what are we [the treatment team] doing? Or why is he [the patient] getting treatment? They’ve got two kids, spend time at home. But we [nurses] don’t actually go out there and tell them [patients], ‘Spend time with them [family].’ I've heard from nurses who do that, though, but these are the more confident nurses that'll be like... you know, I think it's better to spend time at home, or spend summers at home. (Raylene, auto unit)

Nurses expressed a concern about how they made sense of their work and felt a need to maintain some sense of hope for recovery alongside of the knowledge that a patient may die. For instance, Zhanna questioned the purpose of her work when patients did not recover or “make it.”

And I know, like, a part of me, I know she's not going to make it. But then a part of me... I just keep thinking, I hope, I just hope. Because how could you ever work on this floor if you can't hope that somebody's going to make it? (Zhanna, allo unit)
Nurses wanted to show compassion for patients’ suffering, but were often afraid of the repercussions if they were too closely connected or involved with patients and their families. So, sometimes they detached themselves from personal involvement.

I guess…have a little sympathy or compassion, that’s always good. But don’t get yourself too emotionally attached, still keep a very professional distance. I know…I mean I know nurses that are very close to some patients, and good for them if they can deal with it, but for me, personally, I find that if I can detach myself then I can deal with it better. (Samantha, auto unit)

Nurses were understandably concerned about families whom they perceived as difficult due to families’ anxiety or anger about patients’ situations. They feared legal ramifications when families appeared to anticipate nurses “making a mistake,” as Zoey stated.

Sometimes it’s hard [to take an angry patient] because I am almost afraid to take care of the patient because I'm scared that I'm going to do something wrong or somebody would tell me that I was doing it wrong. (Megan, auto unit)

But they’re almost expecting you to make a mistake sometimes. That’s the impression we get, because they [the family] write everything down. (Zoey, allo unit)

Nurses also feared repercussions from doctors or other clinical team members. They feared that being over-involved would impede their (objective) clinical judgment.

It makes it more difficult because you’ve got to get rid of…not get rid of this emotional stuff, but if you’ve got a really busy patient medication-wise or bolus-wise. You can really make a mistake by just getting caught up in what's going on, with that. (Betty, allo unit)

Additionally, nurses feared blame for saying the “wrong” thing, which might be seen by other clinical staff to upset patients, to contradict other healthcare providers, or to stray outside their scope of practice. The majority of nurses expressed a need for more understanding, skills, and practice for how to properly respond to patients’ existential distress.

A lot of the times I don't explain medical things to them [patients/ families]. I let the doctor do that because I don't want [laughs nervously] to tell them the wrong thing. (Tess, allo unit)

I think the nurses should be doing that [telling the doctor to stop aggressive treatment]. I don’t think we do a lot of that, though when you are an advocate for the patient, and you
take the doctor aside and you say I think this is enough, I think the doctor will...we let the
doctor make the decision in the end. (Julia, auto unit)

As a consequence of avoidance or detachment from their patient involvement, nurses
experienced regret, and questioned the meaning and hope in their work. For instance, sometimes
nurses helped patients avoid knowing about the possibility of death. While these actions were
detrimental by minimizing the patients’ worry, they also augmented nurses’ regret in not having
addressed patients’ distress and dying.

A lot of this stuff I sugar coat it, especially with the patients. I'll be...they’ll be, like, ‘Oh, so
what's my platelets today?’ ‘Oh, it's a little low.’...I'm not saying your platelets is four
and you're going to bleed, you know, it's just...a lot of it is sugar coated, when I do tell
them. Or they’ll be, like, ‘What's my temperature?’ I'm like, ‘You're a little warm, you
know, it's 38.’ I don’t tell them...‘You might be septic.’ (Raylene, auto unit)

But if they ask me, ‘Am I going to die?’ [The nurse replies] ‘Well, yeah you're going to.
We all are going to die at some point.’ But they do know...Usually there's a lot of silence
after that. (Betty, allo unit)

Nurses who were more invested in the technical tasks of fighting cancer more often
questioned the meaning and hope in their work when patients faced imminent death. Life-saving
tasks gave concrete meaning to their care but diminished the larger meaning given to “making a
difference” for individual patients and their families.

But I don’t really know—I don't know if it's just that I think the more patients, the more
dying patients I've been around, the more comfortable I am with death and the idea of
death. Being able to say, ‘I did a good job.’ Sometimes it's hard to say that around...like,
I'm nursing a dying patient, and I did a good job today. (Julie, allo unit)

People say, ‘Thank you for helping me.’ Or ‘Thank you for fixing my pump,’ and stuff,
but it's different, you know, being told we really appreciate you coming in here. Or
talking to you has helped us. You don’t really get that. And a lot of times I wonder, did I
even make a difference today? Was there even any point in me being there? (Zhanna, allo
unit)

Some nurses were unsure whether they “did everything” they could to alleviate patients’
distress or improve hope in their situations. At times, technology was of no use beyond giving
patients the capacity to control their bodily suffering. Ways to provide supportive care beyond
biomedical limits were not intuitive to some nurses. Nurses’ frustration or despair overwhelmed them in moments when they could not alleviate patients’ existential distress.

So that set her [the patient] off even more. So she was screaming. She wanted a psych consult immediately because she needed to be sedated. What else?! Asking for Gravol because it has some sedative properties to it, maybe it would calm her down. Just very…Looking for anything and everything to calm herself, and it got to the point where I just got so frustrated. Because you're supposed to be a professional and keep your composure. [So] that I left. I said I can’t deal with this right now. (Potter, auto unit)

Well, he [the patient] goes ‘I got really ashamed that I'm going to die and it’s going to be easy, and I’ll miss my family and my friends.’ And I remember I was doing his dressing and I just started to cry. And he just kind of looked at me and he goes, ‘Oh this job is too hard for you, you should stop.’ And then afterwards I thought you know what, I really let him down. Well, because here he wanted to share this with me because we had this really nice connection and because he wanted to talk to somebody, but because I got so emotional and started to cry, he never brought it up again. (Betty, allo unit)

When patients were recognized by nurses to be dying and sometimes did die on the units, some nurses did not question whether or not they could have done more, but what more could they have done.

Well I felt I didn’t do much. Every time…I don't know, it must just be me, every time a patient was transferred to the ICU or something, I always feel like I missed something or I didn’t do enough. Like maybe I should have been more keen on observing this and that. Just to report to the doctor, something like that. I don't know. (Megan, auto unit)

After, I wonder what happened to the patient from the last time I left. Did I miss anything? And that’s what I always do. That’s why I ask—where I look at the chart and I see what's happened the day after. But that’s just me, I don't know if other nurses do that. (Raylene, auto unit)

At other times, nurses expressed frustration and helplessness when they were unable to address the emotions that patients experienced as a result of awareness to the threat of their mortality. For example, Carrie explains that a patient’s situation did not afford the team any time before the patient suddenly died, and Shania told me that doctors inappropriately prescribed medications that prevented talking to the patient.

Sometimes it happens so quickly…She [the patient] came, she didn’t even get any treatment, she coded, she went to ICU, she died...We hadn't even begun to treat her yet. So I'm just saying, sometimes we don’t have the time to do it…but a lot of times that need for…totally is missed…unfortunately. (Carrie, auto unit)
In our [the life-saving team] case, you know what we do when somebody's really distressed and anxious? Well, let's just prescribe some Ativan or maybe some Haldol, because it's their [the doctors] way to keep [patients] from being restless and confused. So we plug them full of drugs so they're in a stupor. (Shania, allo unit)

The more that the nurses identified with life-saving technology and its ability to “fix” things, the stronger their feelings of loss and shame when patients deteriorated. They felt unable to address concerns (the patients’ and their own) beyond the limits of life-saving technology, and yet they were aware that patients’ concerns had moved past those limits.

I mean I know she's [the patient’s] going to die, but there's a part of me that hopes that every single one of these people leave [the hospital alive]. And there's a part of me that kind of goes...and I know they're not. They're there for at least a month the first time, and then goodness knows...I think the reason it's not depressing is because I still hope...everybody [other nurses] told me, ‘Your patient's not going to make it’ and I think, well, you never know. (Zhanna, allo unit)

Nurses expressed regret and/or guilt about what patients endured due to treatment, especially when they had a better quality of life prior to the treatment, or when patients themselves later questioned whether their treatment had been worthwhile. The concern appeared to be essentially whether gaining quantity of life justified suffering loss of quality of life.

They come in saying, ‘I know I’m going to get through this. I know this is going to be fine. I know, I know, I know.’ And then depending on how the course goes, a lot of times I think, probably in about 90% of the patients, at one point or another, they say, ‘If I had known, I may have made a different decision.’ Even in those patients that are having all those expected side-effects that you know are going to get better. There’s a lot of them that say, ‘Well, if I would have known. (Zoey, allo unit)

He died in the middle of the chemo. You know what, I said, ‘Why start a chemo on a person who's almost dead?’ They could've sent him home and could have had a week with his family in...because he went home and he came back for more treatment, and I said, ‘I hope they don’t start chemo on this guy.’ We did. We gave him chemo. I think it was the second day and he was very sick, and he died. (Chopin, auto unit)

Nurses who were unable to tolerate their emotional involvement with patients and their families or who witnessed other nurses becoming desensitized and detached, questioned the meaning of their work and stated that they “had had enough” or stopped working on these units.
The distress of dying patients cumulated when it was unresolved or when nurse nurses could not acclimatize to the conflict and worry about their experiences.

There was something someone said to me when I first started. They said, ‘You know what. You get used to it eventually.’ And I thought to myself, I don’t want to. Who wants to get used to people dying and not caring, you know what I mean? And [it’s] sort of true, to a certain extent, because you can't cry for everyone.” (Zhanna- allo unit)

We had a nurse on one of the floors and he was an ex-minister. This is what he said to me…After a year, he said ‘I would like to know how you cope with this’ he said, ‘because it's like the Sisyphus myth. This is what I think; we roll the rock up and we get to the top and it rolls back down and we do this on a daily basis. And it was draining. I feel like I just want to give up hope all the time, it's really getting me down.’ And he left and works [name of place] now. (Kandy, allo and auto units)

Yeah, the thing is, every time that patient gets sour, or goes down on the ward, she would start bawling too. And the family starts bawling, she would start too. And that’s why she has to leave. Because she said she can’t handle the stress of all the dying in here. (Megan, auto unit)

Releasing Tension Created by Nurses’ Conflicting Concerns

Sometimes nurses used humour to release the tension of their work. Nurses’ narratives revealed that powerful positive emotions were needed to counterbalance a sense of “doom and gloom,” as Shania said. I sensed that sarcasm was cathartic and helped nurses to distance themselves from the awareness that their own lives were finite.

I’ll meet up [with other nurses] in the med room, pulling meds. You just vent. And I tend to make light of things, you know if someone…even if someone’s dying, there's still humour. You can still have fun with people and their family. Life is too short to take everything so seriously that it’s you know, it’s just…I think it’s just your outlook individually and how you cope, but yeah, we laugh, we laugh a lot. (Potter, auto unit)

Do you know it might be hard, but I think a lot of them [other nurses], it's very cathartic for them. Because you don’t… you talk amongst yourselves, but nurses do tend to get that sort of cynical black humour almost, and a lot of times that’s the way of coping. You don’t mean the things that you say, but you know, ‘circling the drain,’ for example. The term, ‘circling the drain,’ when you really start to think about that, that’s awful. But that’s… you know, ‘How's it going, oh, so-and-so is circling the drain.’ Oh, you know, that kind of thing. (Shania, allo unit)

Releasing the emotional burden with nursing colleagues occurred spontaneously and informally, when they had the time and space to support each other. I saw nurses regularly check
in with others and schedule assignments that allowed each nurse a break from primary patients, considered emotionally “heavy” or ”draining.”

I have to unload at work, my emotional stuff, with the nurses…usually. If something really stressful or heavy is going on in the unit, it's good to just sit down and [lowers voice] talk. (Tess, allo unit)

Our nursing staff is so supportive. We'd be giving each other hugs and supporting each other in the hallways and sometimes just taking...saying, ‘You know what, you take a break from that family, and I'll go in.’ (Julie, allo unit)

I would often just exchange with him [another nurse], and say, ‘Do you want my…’That’s a general thing that we nurses do. We comment, and sometimes if someone has a heavy patient, a heavy assignment, I comment, ‘I have a really heavy assignment.’ You know the good ones, at least, most of us will say, ‘Do you want to exchange?’ (Carrie, auto unit)

Nurses expressed a need to release the tension created by their conflicting concerns in order to re-engage with subsequent patients and to maintain contact with the families of patients who died. As a natural and temporal progression of their emotional tension, there was a different kind of release that began when they recognized patients were dying. Enormous amounts of energy were required to block the tide of emotions each patient evoked or to manage it and prepare for their own sense of grief or bereavement.

I kept thinking if I do, I have to have time to just sit with him. It was a lot. It was emotional. It was a lot of emotional. I thought if I go in there, it'll be hard to just focus on anything else because I got to know him so well and I really liked him as a person. (She starts to cry.) It still breaks my heart when I think about the man and I see that painting all the time. Sometimes I tell people and sometimes I don't. (Shania, allo unit)

If there was no safe outlet for the expression of nurses’ grief, it accumulated, and nurses felt emotionally drained even before the patient died. Sometimes, as in Snook’s situation below, it led to her taking a leave of absence for one year from work.

When I first came here, there was an old gentleman and he was my buddy. I got to know him, his wife and he has a daughter that used to be here as well. And his son came once in a while. But him and I were really good friends. He's an older gentleman who wasn't doing very well. He was re-admitted. He knew he was... in this instance, I couldn't... It was hard for me to come to terms with the fact that he was dying. (Shania, allo unit)
Commonly, when nurses experienced a sense of safety while on their vacations, or when finding time alone with colleagues, they allowed a controlled release of their grief.

Sometimes when a patient dies, the nurses are emotional. There's been several occasions where all the nurses will be crying in the back room or something, or if something really tragic happens too. Mostly the team...the nurses, the doctors, I think everyone is really good at supporting each other. (Tessa, allo unit)

We usually talk about funny narratives, like the good narratives. Where a patient said something funny or something they did or something about their personality that we really liked and it's good. I think that that’s good for us, that we do. I don’t think we realize that we're doing it for a purpose, but I think it does serve a purpose. (Julie, allo unit)

For other nurses, their grief required a more immediate release. Potter expressed a sense of liberation when patients died or were discharged home to die. Julie reported being able “to breathe” again after patients died, free from their involvement with patients.

I wear my heart on my sleeve and you know what I'm thinking when I'm thinking it. So I tend not to carry things around. Like if I'm going to cry, I'm going to cry. If it’s going to be at work, it’s going to be at work. Who cares? Yeah, work, as soon as I walk through those doors, I'm done. It’s too much of a burden, really, to be walking around with all of this extraneous stuff in your everyday life, when you're in your civilian clothes. It’s not worth it. (Potter, auto unit)

Some deaths are also a relief, you know, after you see somebody go through so much, I never thought I would feel that, that was a surprise to me. As a nurse, to say you know what? I felt like I could breathe, this sense of, oh it's over. All that suffering and all that on one person, one human being [sighs] is done, and they can now...yeah. It's like another—I can't even explain it...but, it is a relief, sometimes. (Julie, allo unit)

Many nurses were concerned about blurred boundaries between themselves and the patients and their families. The intimate care they engaged in privileged them with access to particular and private parts of patients’ lives—a part made public to very few people. In recounting how she attended a patient’s funeral, Julie questioned norms of professional practice, and worried that her presence might trigger further suffering for the patient’s family.

But there are three of us that decided, the nurses...that decided to go to the funeral. Two very experienced nurses, they were probably there for about 20 years or more. And then me, who's the new kid on the block. I'd only been there about a year. So I was really...you know, I was questioning it a little bit, thinking, is it okay that we go and how's the family going to feel, are they going to see us and associate us with the death and all the
hospital? I just wasn’t sure how the family would accept us there and how they would react. (Julie, allo unit)

In Julie’s story, the family expressed their appreciation and gratitude for the nurse’s presence at the funeral. Moreover, Julie experienced closure that she acknowledged, not only from her work trying to save the patient, but the emotional work involved in the patient’s dying. Julie valued equally her patient’s illness experiences and end of life. Both afforded her a way to acclimatize to the patient’s death.

This family was just so happy to see us, I've never...it was the last reaction I expected and it was just this like, ‘Oh it's okay. It's okay that we're here!’ I don't know why I was so caught up with how are they going to react, and are they going to be okay that we're here. They were just...smiled and they saw us across the way and they were just...waved, and I thought ‘Okay, it's okay that we're here.’ And in a way it was amazing to see her life, because we saw the healthy life that she had. And they had this slide show...All these prizes, medals and things that she had won throughout her life, and met her friends and her family and it was... I did find that it gave me closure. I thought, ‘I'm saying goodbye and it's okay. She had a great life.’ And I felt like I knew her better, too. (Julie, allo unit)

Only two of the nurses had attended a patient’s funeral. Although Julie talked about a positive experience of attending a patient’s funeral, she never attended another one. Nurses who had not attended a patient’s funeral expressed some fear that the emotions that they anticipated a funeral would evoke would, as Megan stated, “drag them down.”

Because…I don't know, it’s just too much connection. I think. I don't know, I've never been to any one, so I don't know how I would react, but it’s just nurses would tell me we really don’t go to funerals because...what they call this. It would just drag you down. You can’t handle all these funerals. (Megan, auto unit)

Nurses expressed the ability to compartmentalize their grief, in order to leave it behind and focus their energy on looking forward to their involvement with the next patient. By putting it aside, nurses created the capacity to control their concern about matters they were not able to control, such as their own possible dying and death and those of their own family members. This way of being efficient with their time protected the nurses from becoming over-involved with patients and their families.
When I first started here, I used to—after I got home—I'd think, oh what could I have done better or what could I have done more? But now it's like, I know that when I'm here, I've already done everything I could, and so when I'm out of this building, I leave my work behind, I don’t think about it anymore. (Samantha, auto unit)

I really stop thinking about how many people die. I really stopped thinking about it. Somebody goes, ‘You get acclimatized.’ I never really thought... I thought, when they said it I thought they meant you won't care that they die. I didn’t really think they'd mean that you’d learn to cope in your own way. And I guess the way I coped is, I just don’t think about it. I just push it aside, and don’t think about it, and go onto the next person that I may or may not be able to help. (Zhanna, allo unit)

Some nurses (particularly on the allo unit) expressed that existential beliefs, rather than formal spiritual or religious affiliations, were helpful. There was a sense that end-of-life care was directed in part by something greater than themselves and patients’ deaths had cosmic (i.e., spiritual or religious) meaning or purpose for nurses. Importantly, while nurses did not necessarily define their existential orientation as part of an organized religion, they did express how their personal beliefs or philosophy of life enabled them a capacity to work things out with others or with something greater than themselves. Moreover, nurses’ sense of their existential self afforded them meaning of patients’ suffering and deaths and contributed to them a kind of positive reward or meaningfulness in their work.

Yeah, we just chat. Maybe it gives us some sense of...[Interviewer: closure?] Yeah… they're in a better place than here. They're not suffering anymore, and yeah, we just chat about it. (Julie, allo unit)

I am spiritual; I believe in God. And I think that where I work... Like always tell people, like my fiancé’s mom, for instance, this is somebody that’s upset [her] that I don’t go to church and would like me to go to church more often. But I tell her, with what I do, I see how God works, like up close and personal. I can see that type of situation and I see the struggles and I see the rewards, and I see forgiveness and I see all of that stuff. Like I don’t...I believe in something different than what I see at church. I’m very spiritual, just not in an organized fashion. (Zoey, allo unit)

When I dream...Dream, yeah, I met him in my dream. I met him, he looked very peaceful. You know what? He had went up into Heaven, without pain, without suffering. (Celine, allo unit)
Nurses appreciated the part-time pastoral service available to patients on their units. Unfortunately, this service was not viewed by management as an essential resource for daily care, as the chaplain worked only about 15 to 16 hours a week, in each of the two BMT units.

Someone that’s really, really helpful on the unit is our chaplin. She works only part-time unfortunately. She was full-time [when the nurse first started work there] and that’s a stretch even. Because she was actually getting let go and all the nurses actually wrote a letter to [CEO of hospital] and to everyone, asking to have her stay, because she’s just such a help. But on those moments where you’re really busy, you don’t have the time to sit down and just talk with a patient. She does that, and her notes are probably my favourite ones to read in the charts because she has different insights. (Zoey, allo unit)

When nurses believed that their care made a lasting difference to people’s lives and was a valuable part of their own lives, they better tolerated the emotions and experiences related to patients’ deaths. Nurses reported an intuitive learning from patients’ experiences, which taught them what they would and would not do if they faced a similar situation. More importantly, they expressed hope that their families, and they, too, would receive care at the end of their lives similar to what they provided their patients.

I just say, even in those types of situations, you know that you’re making a difference in one of these huge-est moments in one of these people’s lives. Their mom dying is something that’s going to stay with them forever. If they remember me as someone that’s even made it a little bit better, I’ve done my job, right, and I can feel happy that I’ve done what a nurse should do, that I’ve done a good job, that I’m a good nurse, regardless that the outcome wasn’t, ‘She’s cured, she survived. (Zoey, allo unit)

If me and you were given a month to live, you want people around you who are genuinely concerned for you and build a relationship with you. It's rewarding. You can give to the family who's in so much need, right, and make their [the patients and families] last month a better month, kind of. You can try and give as much as you can so that they're [the patients]…that way I find is really rewarding because you have that chance to make their limited time or their last time good. (Tessa, allo unit)

Nurses valued the appreciation they received from patients and their families through letters or mementos. These mementos signified nurses’ involvement and reinforced meaning of their work.

We [nurses] used to have a lot of letters that patients write us, whatever, put it up. But I think they filed them away or something. And her [the patient’s] mother had sent a letter to the floor saying, what great care she [the patient] had received and the nurses were so
great. And then she'd put names of some of the nurses that...the primary nurse and some of the nurses, that had been there. (Carrie- auto unit)

The nurses disclosed their continual search to make sense of encounters with patients. These experiences of having a sense of purpose in working with patients often did not end with patients’ deaths but continued in nurses’ imaginations of patients in an afterlife.

There were times that I would be going home, tired from a day shift and I would be dreaming of the patients. Yeah, especially when I was new in here, I was dreaming of the patients. When I close my eyes, I could see that patient who just died on me, or something. (Megan, auto unit)

As nurses told me their stories, what became obvious was how their care depended on their capacity to tolerate, contain, regulate, and trust their emotional responses when patients faced the threat of mortality and were actively dying. As nurses encountered similar experiences with patients, their perceptual acuity was sharpened and guided them in deciding what were “proper” or “improper” ways to respond and cope with their involvement.

Summary

Nurses were engaged with existential care on these two BMT units. Because of the fragility of patients’ situations, nurses experienced conflicting intentions of fighting cancer while preparing for the possibility of letting go as their main concern. Impediments to working “in” and “out” of a curative culture was problematic because nurses were concerned about bursting the bubble of hope while remaining emotionally attuned and situated to respond properly at any point when the patients’ health might shift. Although nurses varied in whether to and how they responded to patients’ existential distress, they perceived primary responsibility for patients’ distress and end-of-life care. Consequently, the majority of nurses expressed a need for more knowledge, training, and practice to respond to patients’ distress and dying. When nurses experienced “good” connections with patients/families/health care colleagues, they found opportunities to open up space to talk about the threat of patients’ mortality. Responsive skills of
involvement included: communication about the threat of mortality and death, letting be and supporting patients to let go, managing technology and preventing technological intrusions to patients, and striving for patients to have easier deaths. Moreover, nurses were concerned with the patients’ capacity and control to limit their suffering and create meaning and well-being that alleviated their despair.

Nurses used a wide variety of strategies to cope with their involvement with patients and their families. While acknowledging one’s own threat of mortality was common, working through this experience was difficult on one’s own. Often nurses attempted to temper their professional and personal roles to cope. However, when struggling to do so, they sometimes avoided, or detached themselves from patient involvement. If they were able to release the conflicting tension of their work once in awhile, they were able to preserve their emotional resources. Although the tension in the nurses’ work rarely completely subsided, it temporally progressed to a grief response when patients died. Some nurses reported continually struggling with meaning and hope about their work. Conversely, when they demonstrated coping effectively, they expressed a lasting sense of purpose and pride in their work.
CHAPTER VII:

DISCUSSION

We are all—all of us—falling. We are all, now, this moment, in the midst of that descent, fallen from heights that may now seem only a dimly remembered dream, falling toward a depth we can only imagine, glimpsed beneath the water’s surface shimmer. And so let us pray that if we are falling from grace, dear God let us also fall with grace, to grace. If we are falling toward pain and weakness, let us also fall toward sweetness and strength. If we are falling toward death, let us also fall toward life.

(In Learning to Fall, 2000, p. 12, by Philip Simmons, who had Lou Gehrig’s disease, born 1958 and died 2002)
The purpose of this chapter is to answer the research questions in an interpretive discussion. The chapter is divided into three parts. The first part is the interpretive discussion organized according to the four research questions. This discussion illuminates nurses’ perceived responsibility engaged in conflicting concerns of fighting cancer while preparing for the possibility of letting go. This perceived responsibility supported them to sustain patients’ sense of meaning of their suffering. Nurse participants’ agency to balance tensions enabled them to temporally shift their efforts from curative goals to possibilities of letting go in some situations. In doing so, nurses restored hope and protected patients from unnecessary distress. However, their narratives also expressed a need to enhance their knowledge, training, and practice in existential caregiving and ways to cope with their involvement with patients/families. The second part outlines the strengths and limitations of the study. Lastly, the third and final part summarizes this chapter.

**Research Question One:**

(1) *How do nurses experience the threat of patients’ mortality?*

The nurses were emotionally attuned (i.e., meaningfully oriented) to a perceived responsibility governing the threat of patients’ mortality. This is a deeply significant notion within the culture of cure and the possibilities of patients dying. I first explicate the concept by drawing on Yalom’s (1980) idea of *responsibility* inextricably linked to freedom. Second, I discuss nurses’ emotional attunement to individual, interpersonal, and cultural meanings that created a concern for nurses about possibly “bursting the bubble of hope” and whether to and how to respond to patients’ distress and dying. Third, I discuss how nurses temporally *shifted* tensions in efforts to prepare patients/families for possibilities of letting go.
Perceived Responsibility for Engaging in the Threat of Patients’ Mortality

In this study, I suggest that nurse participants were constituted by their everyday perceived responsibility for engaging in the threat of patients’ mortality while also striving to facilitate recovery and to ease death. The first clue came during my field observations of the culture of cure and the possibilities of patients dying. Patients’ prognoses brought the threat of mortality and the salience of dying and death to the foreground of nurses’ experiences. The possibility of patients dying was reflected in artefacts on the units. The walls of the allo bone marrow transplant (BMT) unit held several paintings donated by patients who had died, each inscribed with their date of birth and death. Many of the paintings portrayed symbols associated with mystical beliefs, such as angels. I could not help but notice that the artefacts set the tone of the entire unit. Additionally, there were many more artefacts on the allo BMT unit symbolic of the threat of mortality and death than on the auto BMT unit. This reflected the heightened risk of death due to the common complication of graft-versus-host-disease (GVHD) after allogeneic bone marrow transplants. Hence, early on in the study I began to wonder whether these artefacts constituted what mattered to nurse participants.

In this study, nurses were part of teams that fought death by prolonging patients’ lives. Within the culture of cure, nurses were determined to fight cancer and prevent the possibilities of patients dying. Their fight emphasized technical tasks to anticipate and respond quickly to signs that patients might die, but these moments also provided knowledge and opportunities to express nurses’ concerns about the consequences of treatment. Hence, I interpreted nurses’ narratives as reflecting the embodied responses of nurses—responses that revealed a deeply felt perceived responsibility not only for the management of events leading to patients’ deaths but to how to authentically engage with patients when they experienced awareness of their mortality and dying.
I draw from Yalom’s (1980) existential notion of freedom rooted in an awareness of one’s perceived responsibility to create one’s world. He describes this insight as deeply frightening, because it means one is responsible not only for one’s own successes but for one’s failures. I observed nurses hurrying past the mural in the auto BMT patient lounge, avoiding glimpses of me looking at the paintings on the allo BMT walls, and silently reading to themselves the obituaries taped up in the staff conference rooms. I draw further evidence of nurses’ anxiety shown when they recounted their distressing experiences of patients who died. I suggest that the culture of cure and challenges encountered when nurses recognized the possibility of patients dying contributed to nurse participants fearing patients’ deaths and dying experiences.

Upon admission to the BMT units, nurses emphasized the need to instil confidence in the treatment team and to bolster patients’ “fighting spirit” to endure the suffering involved in treatment and to recover. While talk of biomedical treatment and its authority to “cure” did not necessarily allow nurse participants to avoid their duty to save lives, it did allow for some avoidance of the everyday emotional and psychological acknowledgement of the threat of mortality. This all too familiar finding is echoed in literature that supports that the context of acute hospitals do not adequately attend to issues of patients’ mortality and their capacity to be prepared and accepting of death (McCaughan & Parahoo, 2000; McDonnell, Johnston, Gallagher, & McGlade, 2002). In this way, nurses could understand dying and death as a possible occurrence and be less concerned about how patients experienced facing death.

**Emotional Attunement to Patient’s Existential Suffering**

Whenever nurse participants talked about patients’ situations deteriorating, physically or emotionally, their tone of voice notably changed and they related how patient care was emotionally “heavier” or “draining.” These visible changes and descriptions portrayed the
challenges in managing this underlying presence of death and its threat as nurses strived to sustain hope in fighting cancer with their patients. Reference to this emotional burden experience by nurses and patients resonates in literature that emphasizes continual involvement of the existential threat, regardless of the phase of cancer (Chochinov, et al., 1995, 1999; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). Hence, in this study, while the threat of mortality was prompted by future events of death and dying, nurses’ responses were not found to be solely incumbent on patients’ medical prognoses or physical condition.

Despite the attempts of nurses in this study, to sometimes avoid dealing with the threat of patients’ mortality, they did not prevent their awareness [of] a perceived responsibility for it as shown by how they watched over and at times were reluctant to burst their patients’ bubble of hope, even as they recognized patterns of dying. Rather, nurses were emotionally attuned (i.e., meaningfully oriented) to a conflicting concern: helping patients fight cancer while preparing them for the possibility to let go. Unlike the previous literature (Bestall, et al., 2004; Wilkinson, 1991), nurses’ statements and behaviours were not interpreted in this study as consciously ignoring patients’ needs for support. In contrast, nurse participants held two seemingly conflicting intents depending on the foreseen relative risks and their perceived responsibility to attend to cultural, interpersonal, and patients’ individual concerns, as well as those of their families and of the nurse.

The study findings reveal that nurses knew when patients’ despair grew, particularly in relation to their ability to maintain a fighting spirit. For example, nurses watched for cues of when patients lost their sense of purpose. This occurred not only when the patient’s physical condition deteriorated but when patients were given “false hope” by doctors or when nurses or doctors gave the impression that they had “given up” on patients or abandoned patients’ fight against cancer.
Cues of patients’ feelings of loss included expressions of shame, defeat, and humiliation—as a result of decreased bodily integrity or impacts to patients' quality of life. The ongoing monitoring of patient cues in this study was a nursing intervention that was not surprising because the patients were treated in a culture of cure that reinforced the notion that their bodies could be repaired by modern science. Within the culture of cure, patients could remain "in control," feel peaceful, and have their bodily boundaries maintained (Lawton, 2000). However, nurses’ narratives reflected skepticism of the culture of cure in which they worked. When treatments failed, nurses did not infer blame to medical treatment or to patients for lacking a “fighting spirit.” On the contrary, when treatments failed, nurses were concerned about patients’ loss of their former personhood.

Nurses often began their narratives by describing patients’ former distinct individuality, which was gradually eroded by the threat of mortality, as well as likely the physical dying process. In short, nurses were deeply attuned to patients’ existential isolation and, rather than deflect their responsibility for it, they were often concerned about whether to “burst the bubble of hope.” However, often they were impeded due to inherent risks of doing so.

The challenges involved with interpersonal aspects of nurses’ work added to the likelihood of evading their perceived responsibility to address patients' experiences of the threat of mortality. Nurses frequently talked about their interpersonal conflicts with patients and families. These challenges often arose when nurses lacked knowledge of the particular patient’s past and sense of their future. Without understanding the patient’s situation, nurses expressed being unable to acknowledge and understand the patient’s suffering. Additionally, conflicts often occurred with colleagues who devalued nurses’ existential concerns. These conflicts and challenges in addressing patients’ concerns further led to experiences of feeling that the nurses’ existential care was undervalued on the units and even viewed by some nurses as an irresponsible use of their time.
In addition, several aspects of patients, their families, and nurses themselves, affected their capacity to respond to the threat of patients’ mortality. First, findings suggest influences of age, spoken-language and cultural barriers shaped nurses’ capacity to respond to the existential needs of patients. Nurses judged whether to and how to talk about the threat of patients’ mortality and dying based on the patient’s age, and a belief that dialogue about death was more harmful for younger than older patients. Additionally, nurses believed that some cultures favoured aggressive treatment, even near the end of life.

Second, all of the nurses in this study expressed some uncertainty about their capacity and perceived control to engage with patients’ distress and to help them to confront their fears or voice their feelings around their dying, particularly if patients or families were not “coping well,” which often meant patients or families expressed extreme anxiety or anger. Although all of the participant nurses had obtained an oncology nursing certificate that assured some knowledge of a palliative approach, only three had taken a continuing education workshops or seminars to explore its practical application. Benner, et al., (1996) suggest that know-how requires education and practice with patients to enhance ability to apply complex skills. Practice allows nurses to reflect on their impact and discuss with colleagues qualitative distinctions between patients’ and families’ responses. Even while nurses in this study consistently supported patients dying, they often expressed a need for more confidence in their know-how and perceived control to acknowledge the limits of curative medicine and respond to the threat of patients’ mortality. The literature supports challenges among nurses in having skills to deal with the complex communication issues in managing and addressing a life-threatening illness and end of life care (Fillion et al., 2009; Wilkinson, Perry, Blanchard, & Linsell, 2008).

Third, findings of this study suggest that personal experiences of death in the nurses’ own families enhanced their empathic awareness and experiences of the “limit” situation of death associated with patients’ existential suffering. Seventeen of the 19 nurses said that their
experiences of their own family members dying enhanced their capacity for authentic compassion and their ability to coach patients/families in ways that facilitated quality of life and helped them manage the existential suffering associated with a progressing terminal illness. Although there is almost no literature about how personal experience of death in one’s own family support clinicians’ attitudes to engage in the threat of mortality (Hurtig & Stewin, 1990), there is growing evidence that education that draws on previous experiences (personal or professional) can enhance existential self-awareness of one’s own reactions (Vachon, 2010) and a capacity to engage in end-of-life care discussions (Billings, et al., 2009).

Fourth, the literature vaguely suggests that cancer nurses’ spirituality supports them in finding meaning in their work (Schwartz, 2004; deAraujo, daSilva, & Francisco, 2004). Although existential meanings are associated with enhanced quality of life in cancer patients (Mount et al. 2007; Pelletier et al. 2002), there is very little research about whether and if nurses’ formal spiritual or religious affiliation supports their meanings or satisfaction with their work. In this study, 14 nurses stated that they had a formal religious or spiritual affiliation and five (5) stated that they had none. My findings did not point to any differences in nurses’ existential care or meaning in their work associated with their spiritual or religious affiliation. Hence, the question remains, whether spiritual or religious affiliation corresponds to enhancing nurses’ capacity to find meaning and facilitate meaning for patients’ suffering.

In sum, the aforementioned interpersonal and individual aspects influenced nurses’ agency to respond to the threat of patients’ mortality. However, nurses could not ignore being emotionally attuned to this perceived responsibility. They expressed significant concern and at times experienced inner conflicts or dilemmas while dealing with what they perceived as patients’ loss of personhood at the end of life. As such, nurses in this study expressed concerns about suffering beyond the knowledge that patients faced dying and death.
Temporal Shifts in Efforts to Prepare for the Possibility of Letting go

In this study, nurses temporally shifted tensions from their fight against cancer to letting go, intrinsic to how they were attuned to the patients’ will and knowledge of their felt threat of mortality. Despite the previously mentioned desire of nurse participants to flee this perceived responsibility, I came to understand how nurse participants’ engaged in learning to temporally fluctuate some emphasis on either a fight or to letting go. My understanding of emotional attunement comes from Benner, et al.’s (1996) work in which they argue that the emotional tone of nurses’ work directs perceptual acuity and attentiveness towards patients. Indeed, nurse participants’ emotional tone and meanings of patients’ experiences were embodied, and over time, nurses intuitively judged when patients would survive treatment. Benner’s emphasis about the importance of nurses’ emotional tone is similar to Chochinov’s (2005), in that health care providers’ “set the tone” in their presence and attitudes, which impact patients’ basic dignity.

While Chochinov (2006) suggests “diagnostic” questions can assess and intervene upon patients’ uncertainty or death anxiety, Benner goes further. She states that emotional attunement is a much more complex skill. It requires experience in practice and becomes embodied as nurses develop perceptual acuity and expertise. Indeed, emotional attunement to the threat of patients’ mortality is embodied over time as a skill of involvement (Benner, et al. 1996, 1999).

The skill of involvement is a skill that nurses embody after much practice. Unlike novice nurses, expert nurses have developed knowledge and anticipatory awareness to prevent crises through engaged reasoning in clinical dilemmas. Thus, they quickly may respond at the right moment and time, with know-how of what is needed (Benner, et al. 1996, 1999). The majority of nurses in this study were experienced in oncology, and (to varying degrees) expressed knowing how to do what was needed to prepare patients to let go. In this study, letting go was unlike preparing for death as something to control, postpone, and/or make oneself ready for. In contrast, nurses responded to patients’ cues and invited patients and families to talk about their suffering
and imminent death, maintained regular and continuous contact that gave present meaning to their time with patients/families, managed and prevented the intrusion of technology, and gave meaning to acts of comfort described as *more than* tasks, but preserved patients’ sense of their integrity and wholeness.

Benner and Wrubel (1989) and others (Kendall, 2006, 2006a; Tamura, Kikui, & Watnabe, 2006) suggest that emotional attunement reflects how nurses situate themselves in the appropriate way with patients and their families. By doing so, nurses demonstrate empathic, authentic understanding of patients’ existential suffering and develop appropriate responses to patients’ particular situations. Again, findings highlight that nurses were often simply present and listening to patients, which demonstrated concern for empathic understanding of patients’ distress and dying. Even when the patient was unconscious, they cared for each patient’s body in meaningful ways nurses knew *this* particular person.

*Letting go* was constituted by nurses’ intentions to acknowledge the threat of patients’ mortality, to sustain or restore hope, and protect patients’ from unnecessary distress. Nurses co-constituted these experiences with patients by enacting social meanings of the threat of mortality or dying in present moments. Nurses expressed that patients rarely talked about death anxiety overtly, but gave emotional cues indicating their awareness of life being finite. As a patient's end of life approached, nurses in response changed their priorities of care from task-oriented ones to activities that supported *particular* meaning during present moments of being with patients and their families. For example, nurses sang to patients, played their favourite music, or gave them soothing baths. These activities nurtured patients’ capacity to heal and experience peace of mind free from prescriptive control, as part of *letting go*.

Nurses in this study felt a responsibility to families to help them develop *capacity and control* to let go. They encouraged families to remain involved with patients’ care and coached them to say goodbye. When the threat of mortality and the salience of dying had not been
addressed and/or patients died unexpectedly, nurses themselves suffered. This happened when families lived too far away to visit patients or were unable to say goodbye and when patients were perceived to have difficult or “bad” deaths.

In summary, nurse participants’ existential care was constituted by their perceived responsibility to attend to the threat of patients’ sense of an impending mortality, even while nurses, themselves, were anxious about it. This perceived responsibility has not previously been addressed in the literature about nurses working on bone marrow transplant units, even as patients face the salience of dying. Despite a tendency to avoid directly acknowledging the threat of patients’ mortality, nurses in this study knew that patients faced death and the possibility of dying every day. Still, nurses were reluctant to “burst the bubble of hope” without assurance that they would not suffer the consequences of risks in their culture of cure, including tensions in interpersonal relationships with colleagues and with individual patients and their families. As such, nurses experienced patient care as having one foot in and out of the culture of cure. Nurses watched over and shifted some of their fight to letting go when they knew patients were dying and patients/families/colleagues were responsive to non-curative activities. At these moments, some nurses engaged in these opportunities to prepare patients/families to let go. I suggest that, although, conflicting concerns to fight cancer while preparing for the possibility of letting go created stress for nurses, it often resulted in opportunities for nurses to become attuned to the “right time” to fulfill their perceived responsibility to engage with the threat of patients’ mortality.

**Research Question Two:**

*How do nurses engage with the threat of patients’ mortality?*

I wish to reiterate that study findings revealed that the threat of patients’ mortality was influenced by anticipated future events of death and dying, but not incumbent on them. In other
words, the threat of patients’ mortality was experienced in present moments each day with patients. In many situations, nurses explored and then opened up possibilities to engage with the threat of patients’ mortality. Through this process and the use of advance directives, nurses attempted to sustain and restore hope, as a realistic expectation that not only avoided futile and harmful cardiopulmonary resuscitation (CPR) at the end of patients’ lives, but advocated for “easier” deaths.

*Situated Knowledge, Capacity and Perceived Control to Fight or to Let go*

Nurses felt they were best situated to explore whether and how to respond to the patients’ experiences of their threat of mortality and dying. Their proximity to patients, physically, emotionally, and morally, was of critical importance. In this study, nurses expressed pride in their use of the primary nursing model, because it sustained a nurse’s consistent involvement with assigned patients. This connection appeared central to meanings that nurses gave to their work, particularly because they engaged with patients as people rather than as diseased or damaged bodies. As Benner, et al. (1999) found in their study, the nurse-patient connection set up possibilities for comforting, whether in the midst of a medical crisis or in meeting everyday needs. This connection and the nurse’s clinical knowledge (i.e., experiential knowledge, situatedness in the practice environment, and self-understanding) gave nurses know-how to respond in the present moments to cues particular to patients’/families’ suffering.

The meaning that nurses attributed to cues of patients’ suffering was particular to individual patients and their families. Nurses’ interpretations of body posture, eye contact, physical functioning, and body topology were specific to each patient and directed their responses to each patient. When nurses were attuned emotionally to patients, they were able to

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1 a system for the distribution of nursing care in which care of one patient is managed for the entire shift by one nurse, preferably the same nurse whenever he/she is available to do so, to sustain continuity and accountability
make sense of patients’ cues, whether a felt helplessness, loss of meaning, or merely physical
exhaustion. I theorized that nurses’ interpretation of patients’ cues reflected common knowledge
(i.e., knowledge of common patterns in the patients’ situated contexts) of patients’ embodied
threat of mortality and their capacity to tailor their care to comfort patients properly during these
moments.

*Communication about the Threat of Mortality and Death*

According to Benner, et al. (1996), novice nurses develop expertise in clinical judgement
by learning to read relevant aspects of situations and respond appropriately in a socially skilled
manner. This socially skilled manner requires nurses have “global understanding based on the
integration of past experiences” (p. 116). In this study, global understanding of existential care
was facilitated by informal coaching that nurses received during critical points of their work
from nursing colleagues. Talk about the felt presence of a threat of mortality and death did not
directly come up in nurses’ work, whether by other health care colleagues or patients/families.
However, some nurses were comfortable to respond or to invite cues to talk about patients’ end
of life, depending on each nurse reflexivity and integration of past experiences into their practice.

According to Benner, et al. (1996), “there are multiple levels of *truth* that nurses
negotiate with patient and their families” (p. 374). Additionally, Benner, et al. (1996) suggests
that coaching nurses on-site, during, or soon after distressing patient situations, can “improve
their perceptual acuity and responsiveness” (p. 110). The way nurses became finely attuned to
the patients’ perception of their threat of mortality (i.e., their feelings, thoughts, attitudes) was a
skill not only supported by peer support and coaching, but by role modeling behaviours when
nurses were uncertain of what to do. Stedman and Nolan (2007) state that nursing peer coaches
ought to ideally be a good listener, experienced in conflict resolution, and thoroughly familiar
with the socially embedded issues and policies of the work culture. Stedman, et al. (2007)
suggest that peer coaches be employed by the institution’s human resources department to ensure nurses’ confidentiality when they discuss patient situations with a coach. I suggest that issues of confidentiality were important to all the nurses who participated, particularly as all but one participant requested to be interviewed on the unit they worked in, stating that they preferred not to take patient stories “outside the hospital.”

The study’s findings revealed that nurses actively responded to patients’ suffering fostered by relationships with patients, families, and others on the attending medical team. The series of relationships opened up space and possibilities or choices for existential and end-of-life care of patients and their families. According to Benner and Gordon (1996), nursing expertise in caring is response-based. Although there is a tendency to think of skilled individuals as people who apply their wisdom to patient situations (i.e., like a hammer to a nail), Benner and Gordon suggest that this definition does not address the capacities of the patient and family. Rather, nurses’ skilled involvement responds to observations of other highly skilled nurses as well as the patient/family expectations.

*Letting Be and Supporting Families to Let go*

Nurse participants were aware that not all patients fully accepted dying and death, even if nurses perceived the threat of patients’ mortality and recognized patterns of their dying. Given they were confident to do so; some nurses attempted to meet patients where they were in the moment and responded in various ways. Generally, nurses negotiated the way patients controlled their situations. Sometimes nurses responded by “letting be” an awareness for the threat of mortality by following the patients’ lead and offering to talk about what to expect in later stages of patients’ illness or treatment complications. Balancing hope with honesty is acknowledged to be an important skill for health care providers, and as this study supports, appears to be achieved when hope is articulated in meaningful ways for the patient and family (Clayton, et al, 2007).
Although nurses told me about angry or anxious patients and families who were not ready to let go curative aims, they also talked about opportunities to ask patients/families questions that allowed them to perceive their agency for an “easier” death. When nurses recognized that patients were dying, they embodied presence, listening, and engaging with patients’ and families’ existential distress. Nurses purposefully shifted their curative goals to meeting short-term goals that provided personal meaning and purpose to time spent with patients and their families. These interventions were attuned to the existential impact and the importance of living life fully. Nurses’ actions implicitly signaled to their patients a switch to gentle encouragement to let be the process of dying and to attend to helping patients to live life in meaningful ways.

There were few direct examples of nurses facilitating families to let go; common ones were nurses giving patients permission to die, when they told patients they could “let go.” Again, the intent was not to let go of life but to slowly support patients/families to remain involved in ways other than in things governed by curative aims, such as in their communication that provided closure, or in ways that acknowledged patients’ personal dignity and values. In this way, nurses assisted patients to be responsible and “free” in how they wished to use their time and to identify what was valuable to them. Nurses hoped patients/families eventually accepted their intents to facilitate transitions to living life with hope that each day was lived as wished by the patient, potentially leading to “easier” deaths.

In this study, nurses’ responses to the threat of patients’ mortality and imminent death occurred in the “here-in-now” or in moments felt “right” with patients and their families. Nurses’ responses did not “fix” the patient’s body, but were often simply acts of being present and listening and preserving basic dignity. While these moments were not planned, they did require the clinical team’s awareness of imminent death, and/or a willingness to talk about it by both the patient and family. If so, nurses were sometimes able to communicate meaning during present moments of being with patients/families. Yalom (2002) states this makes interpersonal concerns
meaningful in the “here-in-now” (p. 48). He defines the *here-in-now* as what is happening, for example, *here*, in the patient’s room, and in the *in-betweenness*—of the space between the nurse and the patient and *now*, as the present moment (p. 46). Nurses’ responses in the *here-in-now* acknowledged the finiteness of life and conveyed an appreciation of meaning in being accessible, available, and conveying empathy and understanding to patients and their families. This stance also facilitated for patients and their families a sense of existential *freedom* that allowed for individuality and *living fully* within the context of dying through opportunities to maintain identity, personal wishes/ priorities and personal dignity. According to Yalom (2002), this aspect of existential care underlines the importance of health care workers assistance in day to day containment of the threat of mortality and dying that allows for quality of life though maintenance of a sense of meaning and hope.

Nurses in this study possessed and acted on a sense of not only what *might* happen, but what they saw *as* happening to patients. This reflects Benner and Wrubels’ (1989) notion of temporality. Benner and Wrubel (1989) define temporality as “the way the person lives in the present, which is influenced by the past, and is projected into the future” (p. 412). Hence, nurses possessed common meanings of “false hope” and futile treatment in accordance with their experiences of the threat of patients’ mortality and the dying process. Knowledge of this gave nurses the capacity to cultivate *genuine* or *realistic* hope. Nurses talked about facilitating patients’ return home for a weekend to sleep in their own beds, or to attend family events, such as weddings. Cellarius (2008) defines hope not only an emotional state but an active move *away* from the threat of mortality and towards transcendence of one’s own unavoidable suffering. Nurses in this study commonly expressed this kind of hope. They actively attempted to reframe patients’ futures within attainable goals, which strived to give purpose to their existential suffering.
Managing Technology and Preventing Technological Intrusions to Patients

In this study, nurses’ management of technology was also important in providing comfort for patients. However, sometimes technology intruded on patients’ comfort; for example, when patients’ bodies were unduly trespassed during a medical emergency code. Similar to Seymour’s (2000) study of death in intensive care units, nurses’ concern for non-action to protect the comfort of the body was balanced against technological intrusion “causing” death. However, unlike in Seymour’s study, the concern of nurses in this study was not to negotiate a “natural” death but to negotiate an “easier” death. For some nurses, an “easier” death meant reducing priorities of treatment and technology that might interfere with the patients’ capacity to be with their families at the end of their lives. For other nurses in this study, technology was mobilized to preserve the patients’ physical integrity and reduce families’ distress, while also trying to limit the use of it, such as with cardiopulmonary resuscitation (CPR), at the of the patients’ lives.

Striving for Patients to Have Easier Deaths

Recall that the nurses strived for patients to have “easier deaths” characterized by: experiencing comfort, finding meaning in their suffering, expressing a readiness to die, and choosing the way in which they might die. An easier death also meant that family remained involved till the patient took his/her last breath. Nurses’ concern for patients to have easier deaths is similar to findings from Hodde, et al.’s (2004) study of nurses’ definitions of “better quality of deaths” in intensive care units. These definitions included not performing CPR in the last 8 hours of a patient’s life, having someone present at the time of death, and withdrawing life support with ample opportunity to allow family members to prepare for the person's death (Hodde, Engelberg, Treece, Steinberg, & Curtis, 2004). Similar to Steinhauser, et al.’s (2001) study, an easier death meant that patients had named someone to make decisions, knew what to expect about their physical conditions when they were deteriorating, had their financial affairs in
order, had put their treatment preferences in writing, and knew that their physicians (or nurses) were comfortable talking about death and dying. However, barriers to easier deaths occurred when members of the health care team exacerbated fear in patients when medical treatments had “nothing left to offer.” These findings resonated with the ones in this study, however, “having nothing more to offer” was also a stimulus to preparing patients to let go curative control.

In summary, the study’s findings suggest that despite individual attitudes and interpersonal constraints, nurses engaged in facilitating patients’ fight against cancer while preparing for the possibility of letting go through exploring practical dilemmas and being open to patients’ everyday concerns. Nurses developed these responsive skills primarily through peer support, coaching, and role modeling. Steinhauser (2001), who studied people involved with end-of-life care (i.e., doctors, nurses, social workers, chaplains, hospice volunteers, patients, and bereaved family members living in North Carolina, U.S.A.) remarked that, while physicians offer mostly biomedical perspectives of components of “a good death,” patients, families, and remaining health care providers, including nurses, are more concerned with the quality of dying. Similar to this study, findings demonstrated that nurses were more concerned with patients’ quality of dying and not just with realizing a good death.

**Research Questions Three:**

*How does the context of the inpatient bone marrow transplant units situate nurses’ work within concerns of the threat of patients’ mortality?*

Nurse participants experienced the fight with cancer as co-constituted by whether to and how to respond to patients’ distress associated with the threat of their mortality and dying. The predominant cultural risk in the study’s setting of bone marrow transplant units was biomedicine’s tendency to reduce patient outcomes to symptom management and recovery. This kind of reductionism organized and governed hospital culture to anticipate and prevent patients
experiencing life-threatening and distressing crises (Benner & Wrubel, 1989). The work within the culture of cure governed the physical spaces and their content. For example, spaces were filled with medical equipment (e.g., overflow of stretchers and wheelchairs into hallways), and there were few places for large families to congregate, or for family members to stay overnight in patients’ rooms. Additionally, the nursing routines (e.g., what was charted and reported in shift exchanges) did not project foremost concern to the threat of patients’ mortality (with some exception on the allo unit). The nurses’ fight with cancer was rooted in a sense of being able to “fix” what was wrong with the body and oriented nurses to prioritize reporting actions based on objective, analytical decisions. This focus ignored discriminating empathy and understanding of patients’ existential distress. Data from field observations confirmed that the socialized worldview of nurses was constrained by knowledge of biomedicine and technology, which Thorne (1999) states can privilege this knowledge as important and render meanings of chronic illness as irrelevant.

While the fight against cancer continually reinforced a common purpose among members of the life-saving team, nurses expressed concern for patients’ existential suffering and how these demands of existential care shaped their involvement, perhaps more than other member of the health care team. All of the nurses expressed strong levels of involvement with particular patients and their families, but seldom spoke about how they experienced and engaged in existential caregiving with their colleagues (i.e., in patient care notes or in shift exchange reports). According to Benner, Tanner, and Chesla (1996), critical reflection is hindered not only by health care providers’ lack of knowledge and practice but by a culture that makes it unsafe and uncomfortable to discuss or enact forms of care other than dominant biomedical care.

Nurses talked about responding appropriately to the threat of patients’ mortality or patients’ impending death in their use of advance directives. The culture of cure favoured the use of advance directives to facilitate decisions about whether to and how to resuscitate patients. The
aim was to save their lives. Nurses often initiated the process of doctors writing advance
directives, including Do Not Resuscitate (DNR) orders, not only to properly direct action at the
end of patients’ lives, but during and after treatment when they sought to acknowledge suffering
and open up space to talk about the threat of patients’ mortality and possible dying. Hence, the
nurses’ need to establish DNR orders earlier (i.e., when the possibility of death was more salient)
was deemed premature because nurses’ intentions differed from members of the medical team.

While literature states that health care professionals are uncertain about the role that
nurses ought to take in DNR discussions, an anonymous survey in two teaching hospitals in the
USA reported that 48% of staff nurses (N=219) from medical, intensive care, and cardiac
services at two teaching hospitals strongly agreed in their confidence to discuss consent for DNR
orders, though they were less confident than attending internists (68% of n= 217), and more
confident than medical house officers (39% n= 132). Additionally, nurses were the least likely of
the three groups to find talking to patients or surrogates about DNR orders difficult (35% of
nurses versus 24% of attendants and 21% of medical house officers) and most likely to consider
DNR discussions rewarding clinical experiences [62% of nurses versus 47% of attending and
33% of medical house officers (Sulmasy, et al., 2008)]. Similar to the former study, nurse
participants in this study knew that negotiating end-of-life care was a critical part of their role,
though they were often not encouraged neither to advocate for DNR orders nor to initiate these
discussions.

Still nurses were often the first members of the team to encourage patients to talk with
their families about advance directives. They often also helped patients to make a case to other
members of the health care team for end-of-life decisions about whether to fight or let go.
Advance directives opened up opportunities to discuss ways to preserve patients’ control and
capacity to explore meanings that limited their suffering, for example, with the prevention of
CPR. In other narratives, nurses talked about coaching patients to go home to die. Berry and
Singer (1998) suggest that advance directives are a helpful part of the decision process and are even more helpful than a generic living will because cancer-specific advance directives capture the particular patients’ situations.

When nurses in this study recognized that patients were dying and there were no DNR orders, they experienced stress and conflict with colleagues. Nurses found its absence blocked talk that could alleviate distress for families and nurses when both recognized imminent death. As a consequence, nurses were often the ones that advocated a time for DNR orders; mistakenly understood by some physicians and/or families as letting go of life. Rather, nurses judged DNR orders as helpful in preventing technological intrusion to patients and regaining a sense of control over patients’ lives.

There is some evidence that cancer patients and/or their families, as well as clinicians often disagree about the use of cardiopulmonary resuscitation (CPR) and DNR orders (Eliott & Olver, 2007; Ackroyd, Russon, & Newell, 2007). Research about advance directives also shows that even when a DNR written order exists, conflict among cancer nurses and patients/families occurs when they do not share understanding about the meaning of DNR status (Jezewski and Finnell, 1998). If conflicts are unresolved, important patient/family concerns remain: one in four bereaved family members (or other knowledgeable informants) reported an unmet need in patients’ pain management, one in two reported inadequate emotional support for patients, and one in three bereaved family members reported inadequate emotional support for themselves (Teno, et al. 2007).

This study’s findings echo previous research about the occasional inappropriate use of CPR at the end of patients’ lives. Similar to findings of a study about terminally ill cancer patients receiving aggressive treatment (Fairchild, Kelly & Balogh, 2005), in this study DNR orders were not written until patients were near death, making informed consent for patients impossible and even sometimes, for their families. Benner, et al. (1996) suggest that nurses are
responsible to get “adequate attention paid to patients’ responses to treatment and adequate changes made in therapies that are not working well for the patient” (p. 303). Nurses who did not make strong cases for patients’/families’ decisions about advance directives sometimes left patients experiencing futile and harmful resuscitations. In this study, this occurred even when DNR orders were written on patients’ charts. As a result, several nurses felt they and other members of the medical team had inflicted harm and meaningless suffering on patients and their families. Hence, the meaning of their involvement with patients’/families’ suffering was diminished.

In this study, many nurses talked about their journey through crises of confidence when they questioned the limitations of science in saving lives. Within the culture of cure, the limits of science impeded nurses’ sense of agency to go beyond these intentions. Benner and Wrubel (1989) suggest that patients suffer when nurses see only curative aims and overlook their agency in processes beyond survival. My findings reinforced Benner, et al.’s (1989) assertion that nurses’ sense of failure was often based solely on views of a person based on a mechanistic model (i.e., curative control), which left little room for nurses considering matters of significance of their work beyond survival, including matters of pride, shame, dignity, the sense of worth, love, and so on. In other words, BMT nurses, who questioned whether there was meaning in their work appeared to struggle with meanings of their involvement in patients’/families’ suffering.

Research Question Four:

How do nurses cope with caring for patients who face the threat of mortality?

In this study, patients altered nurses’ professional and personal views of their present and projected future lives. I begin by discussing nurse participants’ suffering and ways they coped with their work.
Acknowledging the Threat of (Nurses’) own Mortality

Nurses resisted the urge to acknowledge the growing threat of patients’ mortality, in part because experiences evoked fear for themselves. For some, they felt susceptible to the same fate as patients and this brought meanings of personal satisfaction and growth to their everyday experiences. However, for others, an acknowledgement of their own potential threat of mortality and potential dying weighed heavily on them, and they needed help to understand and cope with it. These nurses’ reactions were understandable, and even justifiable; they wanted to flee the threat of patients’ mortality. However, the study’s findings suggest that completely avoiding the threat tended to minimize any value some nurses experienced when patients’ suffering was not mitigated by biomedical treatment. Recall that, according to Yalom (1980), the closer we are to the idea that we can die at any moment reminds us that we all share a physical connection ending with a boundary or limit of death. While the sources of nurses suffering differed, overall nurses’ narratives reflected reliance for meaning granted by the culture of cure, rather than other sources of meaning connected to the existential awareness of life’s finiteness.

Tempering Patient Involvement

Nurses in this study revealed different ways of coping (or not coping) with crises of confidence about the culture of cure. The findings commonly suggest that nurses experienced conflict and disappointment when treatment did not resolve patients’ distress. Benner, Tanner, and Chesla (1996) suggest that when nurses can no longer make sense of their work through the mechanistic model, they experience a predicament that can lead to conflict, tension, and outrage. While the culture of cure provided important meaning to saving patients’ lives, it did not address the conflicting tension of intents to fulfill meanings beyond “fixing” patients’ bodies.

Nurses, in this study, sometimes coped by avoiding or detaching from involvement with patients/families due to nurses’ experiences of futility, either to anticipate medical breakdowns in
patients’ responsiveness to treatment or in attempts to alleviate patients’ despair, immutable by medical treatment. Additionally, nurses often feared repercussions from physicians or other team members if they became too personally involved with patients and their families, said something that might upset patients, contradicted other health care providers, or at times if they were perceived that they were going outside the norms of their practice. Benner and Wrubel (1989) state avoidance or detachment from patients occurs when caregiving is separated from caring. Caregiving requires giving resources of the self to enable access to meanings of the patients’ situations, hence loss of an agency to do so creates loss of the sense of caring. When nurses lose their sense of caring, they are unable to access what matters in patients’ situations. Hence, they can no longer emotionally attune and appropriately respond to patients (Benner & Wrubel, 1989, p. 372-373).

Nurses in this study were constituted by their perceived responsibility to the finiteness of life. Life-saving tasks rendered resources and concrete meaning to their care but diminished the larger meaning of making a difference for individual patients and their families. Findings revealed that the more that the nurses identified with their ability to “fix” things, and pushed the “boundary” or “limit” situation of life-saving technology, the stronger their feelings of loss and guilt when patients’ conditions deteriorated and died. These findings indicated nurses’ perceived responsibility to the threat of patients’ mortality and death was a huge burden that created nurses’ suffering, and yet often went unresolved and unrecognized by others. In some instances, nurses experienced alienation or isolation of their own existential suffering, believing that others (i.e., some health care colleagues, their own family and friends) did not understand their suffering. Alienation in cancer nursing work is a significant contributor to work stress (Cohen, 1995; Grunfeld et al. 2000).

As with other professionals who work with traumatized people (e.g., mental health workers, psychologists, social workers), the nurses in this study embodied patients’ suffering and
coped by tempering their involvement. Tempering their patient involvement meant that they regulated professional and personal involvement and detachment (Benner, et al., 1996). Some nurses expressed fears that caring “too much” might lead to their burnout. Similarly, some nurses felt their work was sometimes futile and there appeared to be no end to it. Nurse participants attempted to regulate their intense emotions with a release during moments they felt safe to do so (such as when off the unit), on their vacation, or when finding time to talk with colleagues. In a review of literature by Schluter, et al. (2008), peer support of nurses in distress was conducive to improving their coping skills, more significantly than support from managers, family, or friends.

Seasoned nurses in this study reported that novice nurses were at risk of becoming “unbalanced” with the emotional burden of their work. Nurse participants suggested that with more years of experience on the unit and in oncology, they became aware of their perceived responsibility to engage with patients’ distress, particularly when treatment limits were reached. As the emotional burden grew heavier, they lost their capacity to cope with their patient involvement. Yet only by recognizing their emotional burden did nurses learn to temper their patient involvement. Benner and Wrubel (1989) argue that it is “a mistake to think that caring is the cause of burnout and that the cure is to protect oneself from caring to prevent the ‘disease’ of burnout” (p. 373). They add, “the loss of caring is the sickness, and the return of caring is the recovery” (p. 373). To date, the literature has not captured how to support nurses in recovering appropriate professional caring after its loss through compassion fatigue or burnout (Sherman, et al. 2006).

A few nurses in this study alluded to a capacity to cope with patient involvement by tempering their professional and personal selves. Although they valued their connections with patients and their families, they tried to separate this public caring from their personal caring for family and friends. Notwithstanding these distinctions, many nurses said that their most rewarding relationships were with patients and likened these relationships to “friendships.” I
suggest that balancing of nurses’ personal and professional selves allowed them to release
tensions of their relationships and tolerate conflict in their work. Many of the nurses described
different ways of “unloading their emotions.” Some participants used personal habits, such as
changing out of their uniforms, or exiting through the hospital doors, to compartmentalize or
separate themselves from their workday experiences and not “bring them home.” I suggest that
these strategies may have enabled some nurses to put aside the intensity of their conflicting
concerns about patients/families, and allowed them to return to a sense of their everyday normal
through emotional distancing.

Aranda (2001) and Sashara, et al. (2005) report controversy over what level of intimacy is
appropriate in nursing relationships. However, differences between personal and professional
intimacy do exist. Professional caring affects nurses less than personal caring, is
institutionalized, and is learned through formal education (Spichiger, Wallhagen, & Benner,
2005). However, this study reveals that fluctuating empathic understanding of patients'
experiences of the threat of patients’ mortality impacted nurses both personally and
professionally in their everyday work and compelled nurses to balance the resources of their
emotions in their work and life pursuits. The findings about how nurses cope with their
relationships with dying patients is similar to Mok and Chiu’s (2004) findings that when nurses
developed expertise in palliative care, they learned to cope with patients’ suffering by distancing
their own sense of self from their empathic understanding of the patient/family.

Releasing Tension Created by Nurses’ Conflicting Concerns

Study findings suggest that the stressful work of cancer nurses may be mitigated by
opportunities to release tensions created by nurses’ conflicting concerns—to fight cancer while
preparing for the possibilities of letting go. Nurses’ narratives revealed that powerful positive
emotions, such as humour, were needed to counterbalance a perceived sense of “doom and
gloom” in their work. By occasionally releasing the tension created by their conflicting concerns, they were able to “re-charge” and be emotionally available to engage with patients and their families, even after patients died. In particular, nurses released the emotional burden with nursing colleagues during spontaneous and informal breaks at work, and granted nursing colleagues permission to take breaks or exchanged patient assignments to lessen the emotional burden.

Nurses in this study unavoidably suffered in their relationships with patients. Some nurses in this study reported struggling with the loss of meaning and hope in their work. Similarly, literature suggests that health care providers who help traumatized or suffering people often experience burnout and compassion fatigue (Sabo, 2006; Kearney, et al., 2009). *Burnout* has been studied extensively in oncology, intensive care, palliative care, and psychiatric services, as it is more prevalent among clinicians who work with patients suffering chronic or life-threatening diseases (Bressi, et al. 2008). Burnout is gradual, arising from decreased work performance as a result of a mismatch between personal work goals and the work organization. Six stressors of the work environment that contribute to burnout are: workload, control, reward, community, fairness, and values. Additionally, the cultural norms to display or suppress emotions or to be empathic account for additional variance in burnout scores over and above work stressors (Kearney, et al. 2009). The three characteristics of burnout are: emotional exhaustion, depersonalization, and reduced personal accomplishment (Bressi, et al. 2008).

*Compassion fatigue* on the other hand, is a newer concept that differs from burnout. Compassion fatigue evolves from clinicians’ relationships with patients experiencing pain, suffering, and trauma. Compassion fatigue is characterized by hyperarousal to stimuli, avoidance of stimuli, and recurrence of stress in response to reminders (Kearney, et al. 2009). Burnout can lead to compassion fatigue or vice versa (Sabo, 2006). In this study, the culture of cure clearly set up nurses’ expectations to display or suppress their suffering co-constituted by patients/families.
For some nurses, this culminated in expressions of hypersensitivity to patients’ cues of suffering and avoidance or detachment from patients dying.

When nurses expressed satisfaction in being able to openly acknowledge the threat of patients’ mortality as well as their own, it permitted nurses to better cope with their patient involvement. Furthermore, nurses expressed the ability to compartmentalize their existential tension, in order to leave it behind and focus their energy on looking forward to the next patient. By putting it aside, nurses created the capacity to contain their concern about matters they were not able to control, such as their own possible dying and death and those of their own family members.

Some nurses expressed tolerating their concern and uncertainty about the threat of patients’ mortality and patients’ deaths. This uncertainty, while stressful, provided some measure of meaning when they acknowledged scientific limits and trusted other ways patients were connected to significant others, or to a higher power in the world. When nurses believed that their end-of-life care made a lasting difference to people’s lives and was a valuable part of their work, they better tolerated patients’ deaths.

In this study, releasing tension created by nurses’ conflicting concerns about patients progressed to grief when patients eventually died. This embodied relief was a different kind of release from tension of the threat of patients’ mortality. In contrast, patients were acknowledged to be dying and sometimes, did die on the units. In other words, there was a sense of “closure” when nurses imagined patients to be no longer suffering. Other nurses in this study achieved closure by being part of patients having “easier” deaths, or attending patients’ funerals or memorials, which allowed them to grieve.

In summary, the study’s findings supported nurses’ need to cope with their experience of conflict in their involvement with patients. In the process of making sense of patients’/families’ suffering, nurse participants experienced crises of confidence. They had to work through feelings
of disillusionment when reaching the limits of modern science. When they were unable to make sense of their work, these situations created stress and conflict. Nurses often coped by avoiding or detaching from emotional involvement with patients/families. If they were able to work through their stress and conflict, they learned to balance their personal and professional selves, and more specifically contain their emotional distress to their own threat of mortality. Nurses’ experiences often required that they temper their involvement from the threat of patients’ mortality by having opportunities to release tension of their work. Releasing their tension prevented it from culminating in behaviours of avoiding or detaching from patients. Nurses tolerated a certain degree of tension throughout their work until the stress temporally progressed to a release of their grief when patients died. For nurses in this study, “closure” was essential to being able to let go (curative control).

Section II: Strengths and Limitations of the Study

Strengths

I consistently and coherently followed the methodology of interpretive phenomenology. The study originated from theoretical underpinnings of existential philosophy according to Yalom (1980, 2002) and Benner (1989, 1994, 2001; Benner, et al., 1996). Interpretive phenomenology is concerned with implicit meanings embedded in everyday existence. By illuminating these meanings, the study adds depth and empathetic understanding to the essential nature and practice of nurses’ work.

Rigour was ensured by triangulating data sources. In particular, I deepened my understanding in prolonged engagement of participants’ experiences through observations, interviews, and the exploration of artifacts on the units. I also engaged in respondent validation of preliminary findings. Ten BMT nurses questioned meanings I gave to the word “palliative,” which were contrary to meanings in the curative culture. As a result of this, my understanding of
conflicting intentions in nursing existential care deepened and led me to clarify meanings of letting go. Additionally, I conducted analysis with at least two members of my advisory committee at four points during data collection and four points during the data analysis (i.e., investigator triangulation) to increase the credibility, plausibility, and transferability of my findings.

Limitations

Because this is a qualitative study, the findings do not apply to all cancer nurses, nor are they generalizable to cancer nurses in other bone marrow transplant inpatient services. Additionally, the concepts uncovered in these findings (e.g. reliance on mechanical models of a person, need for more confidence and skills, and compassion fatigue) lack causal relationships among them to any specific degree and direction and are limited to associations only (i.e., environmental, relational, and individual).

While the study interviews were of more benefit than harm to participants, I support Corbin and Morse’s (2003) claim that there is an argument for interviewer’s skill and ethics in endeavours to get depth and breadth of understanding about the phenomenon. “Researchers and participants actually co-construct ethical realities during the course of the interviews” (Corbin & Morse, 2003, p. 348). As interviews unfold, cues that indicate mechanisms for coping with difficult experiences are critical to be aware of. According to Sinding and Aronson, (2003), open-ended interviews enable participants “to control the degree of exposure or disruption they will tolerate, and to maintain valued narratives about themselves” (p. 110). As a novice qualitative researcher but an experienced mental health nurse, when participants were upset, they were given ample opportunity to stop the line of questioning; however, all declined, regained their composure, and redirected the conversation where they chose. In several instances, I judged that the participants’ responses were meeting some healthy need to cope with their anxiety. Even
retreating and choosing a different topic was interpreted as a healthy way of coping, allowing participants to put boundaries around narratives that held threatening feelings or experiences. Although my choice to use interviews did give participants voice, and evoked cathartic responses, I acknowledge that knowledge generated may have been limited by the participants and myself included, as a novice qualitative researcher negotiating my role separate from a mental health nurse.

My own professional stance as primarily a mental health nurse may have also limited the understanding and interpretation of nurses’ experiences. I have never worked as a cancer nurse (or as a BMT nurse) and did not have clinical experience to bridge the potential gap between theory and interpretation of BMT nurses’ experiences. While I did spend time shadowing nurses’ practice on the units to provide situated contextual awareness of their experiences, time was limited to approximately 40 hours in public places and spaces of the units, and not to direct observation of nursing practice with patients and their families.

Summary

The consistent and coherent use of interpretive phenomenology revealed nurses’ experiences of the threat of patients’ mortality, not as events associated with dying and death, but as constituting nurses’ and patients’ everyday existence. As such, nurses’ existential care constituted a perceived responsibility in their work. This co-constitution between nurses and patients/families of their experiences led to conflicts between fighting cancer and preparing patients/families (and nurses) for the possibility of letting go. Preparation for letting go was not intended to prepare patients for the event of death, so much as to sustain or restore meaning (if only briefly), partially obscured by mechanistic control or curative aims governing their present moments and possible futures.
To date, the existing literature is dominated by discourse about the mechanistic control of patients’ bodies in the culture of cure on BMT units; however, what is scarcely discussed is how nurses are intuitively attuned to hopes beyond prolonging patients’ survival. In this study, nurses’ care was essentially structured by an awareness of the need to make sense of patients’ suffering, particularly when treatment did not succeed and patients were acknowledged to be dying. In these moments of being with patients, nurses struggled with whether to respond, as well as how specifically to respond, to patients’ suffering. I suggest that nurses’ awareness of their perceived responsibility was tempered by nurses’ personal and professional lives. For some nurses, it was distressing and created feelings of confusion and anguish that had the potential to overwhelm them. Hence, they avoided and even sometimes detached themselves from awareness of this perceived responsibility.

Despite constraints of individual attitudes and interpersonal conflicts, many nurses demonstrated responsive skills of involvement with patients’/families’ distress and sustained or restored meaning of their suffering. Responsive skills of involvement engaged patients in hope of living fully and protected them from unnecessary distress by advocated for possibilities of “easier deaths.” While the majority of nurses expressed a need for more education and training in existential caregiving skills, many appreciated coaching provided by supportive colleagues who were responsive to exploring patients’ suffering and to striving for easier deaths. Nurses’ work took great emotional toll on them, but they also experienced substantial rewards. Despite the limitations of the study, it offered new insights into how nurses learn to temper their private and professional lives and to containing their own threat of mortality.
CHAPTER VIII:
IMPLICATIONS FOR POLICY, PRACTICE, EDUCATION, AND RESEARCH
Policy and Practice Implications

In light of findings from this study, I argue that there needs to be further examination of and guidance in delineating how nursing professional accountability for existential care can be constituted and facilitated for patients, not deemed “palliative” but who experience existential distress and suffering. While national standards of psychosocial oncology exist in Canada (Canadian Association of Psychosocial Oncology, 1999), and psychosocial distress is acknowledged to be the “sixth vital sign” in cancer care by the Canadian Strategy for Cancer Control (Bultz & Carlson, 2005) these standards do not yet coincide with practice where there is conflicting intents of ‘fighting cancer while also preparing patients for letting go.’ Ahmedzai, et al., (2004) suggest refining the World Health Organization’s palliative care definition to reflect increasing multi-professional specialization and different models for delivering palliative care. I suggest that the findings in this study may reflect a different model for entering into palliative care. In this study, the nurses’ reasoning of whether to and how to respond to patients’ distress and dying reflected a need to engage and explore existential questions with the patient/family before responding, thus, considering their intents, before committing to meanings of a palliative care approach. The study findings suggest a need for cancer nurses to consider opening up dialogue about the threat of mortality as an important component (separate from anticipatory events of death and dying), and essential to the transition from acute to palliative care in settings in which patients face highly uncertain prognoses.

Findings from this study suggest that institutional and unit policy leading the fight against cancer can not overshadow perceived responsibility for existential care, as part of supportive nursing care. These findings resonate with Dougherty, et al., (2009)’s study that reported 80% of oncology staff thought their workload (and lack of resources) interfered with their ability to provide emotional support and compassionate end-of-life care for patients. Although policy in this study setting’s two bone marrow transplant units supported seamless patient-centered care
using a primary nursing model, the culture of cure may have better supported nurses’ awareness, agency, and development of existential skills with policies that give value and credibility to this kind of clinical knowledge.

While lack of resources, such as time and staffing, continues to be reported as an impediment to talk that explores existential suffering, I suggest that this discourse may obscure underlying problems shown in this study; that is, nurses’ sense of agency to respond to existential suffering of patients is a very complex skill set. As shown in this study, one part of this skill set may be a sense of presence being with patients’ suffering. In one study by Thorne and Colleagues (2009), communication that created “the illusion of having time,” and encouraged questions to communicate to patients that their experiences mattered reflected respectful engagement with patients’ suffering (Thorne, Hislop, Stajduhar, & Oglov, 2009). Notably, there are very few studies of nurses being with patients’ suffering in a process leading to end-of-life decisions, even in contexts that favour a nurse-patient assignment ratio of one patient to one nurse, such as intensive care units (Baggs & Schmitt, 2000). Hence, I suggest that the dominant discourse about lack of resources (time and staff) may obscure the real problem that nurses face: valuing their knowledge to “see” and “make a case” for the existential concerns of cancer patients in curative cultures that constrain their sense of capacity to respond.

While oncology nursing standards state that advanced communication skills are essential to engaging with cancer patients’ experiences (CANO, 2008), there may be a need for more emphasis on skills of involvement that reflect a felt responsibility to patients’ experiences of distress and suffering. This study’s findings suggest that nurses experienced a perceived responsibility for patients’ distress from the threat of mortality and welcomed more opportunities to develop skills of reasoning and responding to it. The findings also support suggestions in literature (Thorne, 2006) that nurses need to necessarily draw on the expertise of patients and their families. Hence, while skills of how to respond to patients’ existential distress and
suffering may never be normative, the findings of this study suggest that nurses’ advanced communication skills could explore nuanced personal meanings of patients’ suffering and hope; these meanings may support or challenge reasoning through nurses’ own conflicting intents for patients/families.

Findings from this study suggest that a supportive team that promotes existential caregiving may reduce nurses’ work stress. Pierce et al.’s (2007) study findings suggest palliative care unit staff (64% who were nurses) tend to report less work stress, as compared to oncology inpatient staff (76% of who were nurses), due to a supportive team environment. The authors suggest continuing education in palliative models, weekly multidisciplinary clinical team rounds, monthly pain and symptom management rounds given emphasis to specialized needs of dying patients, staff retreats, debriefing, a strong ethic of teamwork, and respect for each members’ contribution on the team are conducive to a sense of team cohesion that could be fostered in general oncology settings. Malignant hematology oncology units, represented by the study’s setting of BMT units, might similarly benefit by open acknowledgement and discussions of patients’/families’ existential distress and suffering. In particular, the supportive strategies to debrief daily and/or in regular staff retreats and monthly clinical rounds about patients’ distress and suffering may enhance cohesive teamwork surrounding the everyday challenges cancer nurses face on these units.

This study highlights the critical importance and practical concern of nurses’ perceived control for their work in their relationships with patients, their families, and in their health care teams. In a study of 63 oncology staff (64% who were nurses), the most important factor influencing the perception of work-related stress was their perception of workload negatively impacting patient care (Dougherty, et al., 2009). Furthermore, other contextual factors that impacted oncology staff’s sense of work-related stress were: the perception of not having enough time to grieve the death of patients, and the perception that there were not enough resources to
cope with work-related stress. Conversely, the perception of being well supported by the hospital predicted less work-related stress (Dougherty, et al., 2009). Similarly in my study, nurses’ capacity to regularly access responsive relationships were the key to nurses expressing a perception that alleviated negative impacts of their emotional burden and supported them to temper their patient involvement.

In summary, this study suggests that formal spaces and places to explore the meanings of patients’ suffering and hope may support their felt responsibly for existential care and reduce their work stress. As a consequence, these opportunities may give credibility and value to cancer nurses’ clinical knowledge of patients’/families’ existential care and influence their own capacity to tolerate and contain the threat of patients’ mortality. In other words, nurses may be able to cope with the daily emotional toll of their work better and enhance their sense of self-care and compassion for their own existential suffering.

Education Implications

National standards of psychosocial oncology have identified a need for formal education for health professionals in this field, but few universities offer undergraduate or graduate courses (McLeod & Dumont, 2008). The domain of psychosocial oncology includes the formal study, understanding and treatment of “the social, psychological, emotional, spiritual, quality of life and functional aspects of cancer as applied across the cancer trajectory from prevention through bereavement” (Canadian Association of Psychosocial Oncology, 1999). While psychosocial oncology is a sub-specialty of health professionals, and not nurses alone, findings of this study support the need for more emphasis on psychosocial education in undergraduate nursing to emphasize principles and values underlying basic nursing care. Psychosocial skills need to be constructed on an awareness and personal capacity to reflect on nurse’s own threat of mortality triggered by their experiences with patients. Findings from this study suggest that nurses
contemplating work on cancer care units, similar to the study’s BMT units, ought to first consider their own personal capacity to engage in the threat of patients’ mortality. This finding is in agreement to a study by Dougherty, et al.,’s (2009) that found that staff (n= 60; 71% nurses) who made a deliberate decision to work in their respective workplace (i.e., oncology or palliative care) had significantly less perceived stress than those for whom this was not a choice.

Findings from this study also suggest that front-line oncology nurses need to develop advanced skills of communication for phases in the trajectory crossing acute and end-of-life care, similar to this study’s setting. Current reviews of communication about difficult topics, such as prognosis, report that while instrumental and technical aspects of providing information are essential, affective and relational aspects of involvement (that is, aspects that establish trust and empathetic awareness) are not well integrated into communication skills training (Hack, Degner, & Parker, 2005). According to my study’s findings, the affective and relational skills of involvement are crucial to engaging and encouraging patients to disclose their existential distress. Theoretically guided by findings of this study, these aspects of communication require training to: i) be present and responsive to patients’ tacit or verbal cues of distress (e.g., What is important today for the patient?), ii) explore patients’ expressions about their distress and dying with open-ended questions that summarizes and clarifies meanings (e.g., What is a personal goal for them?), iii) provide space to contain patients’ distressing emotions and comfort them (e.g., What gives the patient comfort or solace?), iv) problem solve and offer strategies to attend to and maintain hope and dignity regardless of the stage of their illness (e.g., How does the patient want to be remembered by their family?), and iv) screen and monitor distress that may progress to mood disorders of anxiety and depression, as well as hopelessness and a wish to hasten death. The responsive skills of letting be and supporting families to let go, managing technology and preventing technological intrusions, and striving for patients to have easier deaths adds further communication skills to advocate and make a case for patients’ /families’ mastery and control of
their situations. By reaching their short-term goals (e.g., projects, visits with important others), patients can maintain hope as illness advances.

In this study, the clinical knowledge of nursing existential care was not visible on patients’ charts or information passed on in shift exchange reports to colleagues. Given the everyday proximity of nurses to patients/families, findings of this study support continuing nursing education focused on reasoning through opportunities to talk about patients’ distress and to enhancing their dignity. Benner, et al. (1996) state that nurses’ inability to experience their practice as embodying clinical and ethical knowledge prevents a sense of appropriate action and creates uncertainty. Moreover, this uncertainty invites deferral of responsibility for clinical decisions (p. 182). Indeed, nurse participants embodied the stress of their responsibility for patients’ existential distress, but minimized or deferred their perceived control for their stress, not knowing how to be responsible for it or perhaps even feeling embarrassed. Hence, I suggest educating cancer nurses to become better guides to alleviate patients’ distress may shift curative cultures to valuing this kind of knowledge and supporting nurses to talk about it during shift exchange reports and to document it in their patient care notes.

Currently, the deSouza Institute (2009) in Ontario, Canada, offers psychosocial training to front-line oncology nurses in a one day continuing education workshop. The workshop introduces screening, assessment, and methods to address psychosocial, including existential distress. As well, they offer a 13 week web-based continuing education course for graduate students of partner universities and practicing health professionals, called the “Interprofessional Psychosocial Oncology Distance Education (IPODE) Project /Canadian Association of Psychosocial Oncology” (deSouza, 2009). Courses such as these offer skill building and tools defining “what is distress” and how to assess it using strategies to engage in conversations about how to manage distress. In addition, these approaches are expected to be further developed for
nurses through ongoing mentorship and coaching for embodied skill-building and maintenance to address complexities in cancer care (deSouza, 2009).

In this study, coaching by “more experienced” nurses was suggested to be a helpful resource for modeling and building confidence in existential skills of responsiveness. Coaching is a strategy used in literature with nursing peers that encourages critical reflection of their perceived responsibility in their work (Stedman, 2007). Coaching using narratives that compare how one patient’s situation is similar or different from others is a way to critically reflect and “see” qualitative distinctions among different patient situations (Benner, et al. 1996). Benner, et al. (1996) state that when nurses have the space and time to share their narratives, they can commiserate and learn from each others’ skill of involvement. These skills provide them opportunities to learn tools and techniques (i.e., interpersonal process, advanced communication) that judges when to and how to respond to different patient situations. In this way, nurses learn that they do impact patients’ suffering.

Research Implications

The study’s findings suggest three key areas for future research. I will broadly discuss all three and then highlight the area I plan to pursue in my research program. First, while these nurses experienced a perceived responsibility to fight cancer, while also helping prepare patients for the possibility of letting go, it is still unclear whether and how patients expect nurses to address these concerns. In this study, similar to another (Lawton, 2000), the culture of cure socially constructed relationships, and the formerly private individual was made a public patient dependent on nurses’ and physicians’ agency. Hence, there is likely an expectation from many patients that nurses would be expected to support the agency of patients to meet their existential needs. Indeed, in a recent hermeneutic-phenomenological study by Charalambous, Paspopoulos, and Beadsmoore (2008), cancer patients held expectations that nurses would go beyond the
simple provision of information to ways of being therapeutic by conveying emotions, and thoughts and worries to and from patients in ways patients felt valued. Patients expressed a need for nurses to seek meaningful interactions through a personal connection to them, which coincided with meanings of spiritual and religious caregiving (Charalambous, et al., 2008). Future research of patients’ expectations of existential care is needed to support these conclusions.

Second, while this study suggests nurses influenced patients’/families’ experiences of their distress and dying, similar to literature, there is little evidence that nurses’ communication skills alleviated patients’ level of anxiety (Wilkinson, Perry, Blanchard, & Linsell, 2008). While communication skills may support nurses to be more emotionally attuned to patients’ distress, they have not been found to be sufficient to increase the specific detection of psychological distress or to respond appropriately to patients’ distress. Similar conclusions are suggested in a training program, that attempts to go beyond communication skills to support health care providers to screen for psychosocial distress, to appropriately respond with patients, as well as support staff themselves (Jenkins, et al., 2010). However, my study findings suggest that developing existential skilled involvement requires not only knowledge that patients suffer existential despair, but knowledge of how-to respond based on broader personal, relational, and cultural work influences, which may require practical experience and coaching. Hence, future research is needed exploring how to tailor communication training to nurses in varied situations with patients/families, and to different work cultures in cancer. This kind of specificity in research is clearly needed where personal values are explored according to increasing complex situations that hold conflicting intents with patients/families. Communication strategies that respond to these varying situations may require exploring different models of communication (i.e., to titrate conditional to full disclosure and negotiate goals), followed by coaching or mentorship to enhance competency and confidence in skilled involvement.
Third, the findings suggest that nurses can better cope with patients’ and their own existential suffering inherent in their work if they learn to temper their own personal and professional involvement and release tension in their work. Findings of this study suggest that BMT nurses often experienced the tension in their patient involvement as “draining.” Hence, their capacity to contain the tension for patients/families in their professional role and for their own threat of mortality was stressful. They sometimes resorted to detaching or avoiding patient involvement with “difficult” patients (i.e., those who were dying, or expressed hopelessness, anxiety, anger, or depression). However, study findings suggested that by creating an atmosphere where nurses felt supported and their existential care was acknowledged (i.e., informal discussions among nurses or in the group led by the chaplain), they felt more open to taking risks beyond aims of prolonging life and responding to patients’ distress. While these findings are supported in a review of cancer nursing research (deAraujo, daSilva, & Francisco, 2004), further research is needed to explore the processes to support nurses to better tolerate stress and find meaning in their involvement with patients’ suffering, often unresolved by curative aims.

In general, there is a need for more research in educating, skills training, and supporting nurses in advanced communication and interpersonal processes associated with patients who experience existential distress. In doing so, nurses’ communication would not only address the instrumental and technical needs of providing information to patients, but would integrate affective and relational aspects of health care communication (Hack, Degner, & Parker, 2005). The areas I plan to pursue in my research program will focus on designing studies to reveal existential practice competencies (i.e., responsibility awareness, felt agency beyond curative aims, contextual resources, and advanced communication skills), explore the ways in which nurses may develop these skills, and explore measures of competency in existential care.
Summary

Study findings indicate that there needs to be a comprehensive approach to establishing nurses as credible guides in existential care supported by health policy, institutional, and unit policy. By enhancing cancer nurses’ perceived control in their relationships with patients, their families, and their health care teams, they may find meaning in their work beyond the limits of biomedical treatment that reduces work-related stress and contributes to their retention in practice. Education in psychosocial care may need to give more emphasis on principles and values underlying basic nursing care in undergraduate nursing curriculum, and in continuing education and coaching with front-line oncology nurses. Credibility given to clinical knowledge of patients’/families’ distress and suffering needs to be integrated in research of advanced communication skills and to the exchange of this kind of knowledge among health care teams. While research is beginning to explore existential processes and patients’/families’ expectations from nurses in settings similar to the one in this study, there is a need for more research in other areas (perhaps not only in cancer) that hold ambiguity of conflicting intents and to illuminating what are the competencies and measures of nursing existential care. Finally, the manner in which nursing existential care may be taught needs future research in how skilled involvement requires not only knowledge of patients’/families’ suffering, but to knowledge of how-to respond based on broader personal, relational, and cultural work influences.
Epilogue

*It’s only from the heart that one can see rightly.*

*What is essential is invisible to the eye.*

By Antoine de Saint-Exupery From the book, the Little Prince (1943),

Orlando Florida: Harcourt Inc.

When I started my doctoral studies, I was angry about the insensibility of death in my life. My experiences brought me suffering unlike that which I had known before because I didn’t know how to be responsible for “fixing” it. Nor did I want to be responsible for it. But I did feel responsible, not just to myself, but to the world of others affected by Loletta’s death. Now after seven years of searching for how to make sense of my suffering, I wish I could say that I have done just that. But I am a work in progress, and can only say what I know so far. I know I’ve succeeded, but only in as far as I was willing to explore what suffering meant and had opportunities to learn from others, most significantly, the nurses in this study, my supervisor, and my advisory committee. They taught me a crucial lesson: suffering, itself, has meaning.

This is what I have learned so far: When I love someone, suffering is unavoidable. Even in my best love stories, my loved one eventually became ill and died, and I was left to suffer. Hence, I’ve learned that nobody can expect to love someone and avoid suffering. While this kind of everyday suffering was difficult, my suffering was much greater when trying to make sense of it. Indeed, feeling responsible each day for my life and my suffering, as well as the lives of others I touched, was overwhelming. I could not help but try to avoid my felt responsibility by depending on others to tell me what to do, or on scientific understanding, or on fate. But eventually I came to realize that I, alone, was responsible for my own suffering and had to assert myself to say and do what I came to feel and know was right.

In short, I had to have faith in myself—*faith, not only in my potential to learn but in my potential to fall.* When I say* fall*, I don’t mean into oblivion or into an abyss where I might wish
for death, but *fall* as a response to unavoidable suffering. Without a doubt, I feel my responsibility to live is much worse than my responsibility to die well. Thus, I learn to have faith in my potential *to fall*, not only towards feeling pain and weakness, but *towards grace*— the grace of enlightenment. I’ve learned that only by falling can I lift myself up to see new possibilities of where and how I belong in this world. In this way, I am transformed and continue to be transformed by my suffering. Now at the end of my journey as a doctoral student, I can finally *see* and accept my suffering *rightly*. 
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APPENDICES
Appendix A
Research Ethics Board Approval Letters

Date: March 27, 2007
To: Dr. Mary Jane Esplin
9EN-242A, TGH
Re: 06-0771-CE
The Nurses' Experience of Being With Cancer Patients who Face the Threat of Mortality

REB Review Type: Expedited
REB Initial Approval Date: March 26, 2007
REB Expiry Date: March 26, 2008

Documents Approved:
Protocol version #2 (dated February 1, 2007)
Nurses Consent Form version #3 (dated March 16, 2007)
E-mail Recruitment Script version #3 (dated March 16, 2007)
Study Explanation (received March 16, 2007)

The above named study has been reviewed and approved by the Research Ethics Board. If, during the course of the research, there are any serious adverse events, any confidentiality concerns, changes in the approved protocol or consent form, or any new information that must be considered with respect to the project, these should be brought to the immediate attention of the REB. In the event of a privacy breach, you are responsible for reporting the breach to the REB and the Corporate Privacy Office (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004). Additionally, the REB requires reports of inappropriate/authorized use of the information.

If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must be notified of the completion or termination of this study and a final report provided. As the Principal Investigator, you are responsible for the ethical conduct of this study.


Sincerely,

RH/tt
UNIVERSITY OF TORONTO
Office of the Vice-President, Research and Associate Provost
Ethics Review Office

PROTOCOL REFERENCE #20012

April 4, 2007

Dr. Mary Jane Espleen
Toronto General Hospital
200 Elizabeth St.
Toronto, ON M5G 2C4

Ms. Doris Leung
Faculty of Nursing
155 College St.
Toronto, ON M5T 1P8

Dear Dr. Espleen and Ms. Leung:

Re: Administrative Approval of your research protocol entitled, "The Nurses' Experience of Being with Cancer Patients who face the Threat of Mortality"

We are writing to advise you that the Ethics Review Office has granted administrative approval to the above-named research study. The level of approval is based on the following role(s) of the University, as you have identified with your submission:

- Graduate Student research – hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board. Should the status (i.e. University involvement) of the project change, please contact the Ethics Review Office to determine whether a new review (administrative or ethics) may be required.

Best wishes for the successful completion of your project.

Yours sincerely,

[Signature]

Jenny Peto
Ethics Review Coordinator
Appendix B

E-mail Recruitment Message for Nurse Participants

Re: Research Study of Nurses' Experience of Being with Cancer Patients on the BMT Unit(s)

If you are currently working as a registered nurse in the hematology/bone marrow transplant unit at [Princess Margaret Hospital] and you provide direct patient care, you are eligible to participate in a research study that will be carried out to explore oncology nurses experiences of being with cancer patients who face fears and uncertainty about the future related to the diagnosis and progression of cancer. The study is being conducted by Ms. Doris Leung, a doctoral nursing student at the Faculty of Nursing, University of Toronto, who is supervised by Mary Jane Esplen, PhD, RN, and clinician-scientist at University Health Network. Knowledge about how nurses experience working with patients who must deal with having a life-threatening illness, such as cancer, and who face aggressive treatments within the oncology setting is not well known. To add knowledge to the nature of this work, nurses who consent to participate will be asked about some of their patient experiences in an interview and will be shadowed for part of one of his/her shifts. If you do not consent to this study, please be aware that Doris may be shadowing one of your colleagues who has consented. In this case, please be aware that Doris will collect no data whatsoever on your participation in interactions on the unit.

Ms. Doris Leung will attend a few) of the nursing and interdisciplinary team meetings in [________________] to briefly describe the study, answer any questions, and distribute information sheets.

Your participation in the study will remain strictly confidential. You will be identified only with a pseudo name of your choice. No names or identifying information will be used in any publication or presentations. No information identifying you will be transferred outside the investigators in this study or in this hospital.

Compensation will be provided. Interviews will occur after regularly scheduled work shifts.

If you would like more information or would like to participate in this study, please e-mail Doris Leung at doris.leung@utoronto.ca or phone her at 647-588-3623.

Thank you.
Appendix C
Explanation of Study for Nurses

Dear Nursing Colleague:

We are conducting a research study on your unit. The principle researcher is Doris Leung. She is a graduate student at the University of Toronto in the Faculty of Nursing and is required to conduct research as part of the requirements of a PhD. The study is being supervised by Dr. Mary Jane Esplen, a clinician-scientist with the PMH-Psychosocial Oncology & Palliative Care Program at University Health Network.

The purpose of this research project is to explore oncology nurses experiences of being with cancer patients who face fears and uncertainty about the future related to the diagnosis and progression of cancer.

If you are a full-time or part-time Registered Nurse or work up to part-time hours providing direct care to patients on the bone marrow transplant units at [Princess Margaret Hospital], you are eligible to participate in this study.

If you agree to voluntarily participate in this research, your participation will include the researcher "shadowing" you for one to two shifts to observe the nature of care and unit routines. Note: No direct patient interactions will be observed. Following this one to two interviews will take place over a period of 4 to 6 months. Approximately 15-20 nurses will be recruited for this study. If you do not consent to this study, please be aware that Doris may be shadowing one of your colleagues who has consented. In this case, please be aware that Doris will collect no data whatsoever on your participation in interactions on the unit.

Your participation in this study is voluntary. If you do decide to participate, you may withdraw at any time without any consequences. If you do withdraw from the study, your data will used only if you give your permission.

Your participation in the study will remain strictly confidential. You will be identified only with a pseudo name of your choice. No names or identifying information will be used in any publication or presentations. No information identifying you will be transferred outside the investigators in this study or in this hospital.

Financial compensation will be given to each nurse participant for interviews that will take place during non-working hours before or after a regularly-scheduled work shift. In addition, a coffee coupon from Tim Hortons is given in appreciation for participating.

Contact for More Information or to Participate in this Study:
Ms. Doris Leung at her email address: doris.leung@utoronto.ca or phone her at: (647) 588-3623. Additionally, you can contact her supervisor, Dr. Mary Jane Esplen, for any questions or concerns related to the study at: mesplen@uhnres.utoronto.ca or 416-340-3024.

Thank you.
Appendix D

Explanation of Study for Allied HealthCare Providers

The Nurses' Experience of Being with Cancer Patients on a BMT Unit

To Allied Healthcare Providers of the Hematology/ Blood Disorders Unit:

We are conducting a research study on your unit. The primary researcher is Doris Leung. She is a doctoral student at the University of Toronto in the Faculty of Nursing at the University of Toronto. As a graduate student, she is required to conduct research as part of the requirements for a degree in philosophy. The study is being supervised by Dr. Mary Jane Esplen, a clinician-scientist with the PMH-Psychosocial Oncology & Palliative Care Program and University Health Network.

The purpose of this research project is to explore oncology nurses experiences of being with cancer patients who face fears and uncertainty about the future related to the diagnosis and progression of cancer.

The study will take place during the months of March 2007 to September 2007, during a period of 4 to 6 months. Approximately 20 nurses will be recruited for this study.

The primary participants are nursing staff. No specific or identifying information regarding allied health care workers or non-participating nurse colleagues will be collected. All discussions about patient care remain completely confidential and in no way will any of their names or any identifying information be used in any of the findings of the research given in presentations or publications. No information identifying you will be transferred outside the unit or hospital.

If you have any concerns or questions about this study, please do not hesitate to contact the primary researcher or her supervisor for more information. Contact information is: Doris Leung at doris.leung@utoronto.ca or phone her at: 647-588-3623 or Dr. Mary Jane Esplen at mesplen@uhnres.utoronto.ca or 416-340-3024.

Thank you.
Appendix E
Consent Form for Participation in a Research Study

TITLE: The Nurses’ Experiences of Cancer Patients on a Bone Marrow Transplant Unit

INVESTIGATOR: Doris Leung, RN, Doctoral Candidate

SUPERVISOR: Mary Jane Esplen, PhD, RN, Clinician-Scientist, UHN

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, inconvenience, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the researcher to explain any words you don't understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Background
A common theme in stories of people who have cancer is the experience of being conscious of living with an awareness of dying. Nurses are the largest group of front-line clinicians who engage with patients’ experiences. However, little is known about how nurses interact within these situations, how confident they feel, or what knowledge base or skills they use to assist patients who confront these realities.

Purpose and Objectives
The purpose of this research project is to explore oncology nurses experiences of being with cancer patients who face fears and uncertainty about the future related to the diagnosis and progression of cancer or the related treatment effects.

What is Involved
If you agree to voluntarily participate in this research, you will be asked to have Doris Leung "shadow" your care for one shift to gain understanding of the nature of your work and ward routines. Note: No direct patient interactions will be observed. Following this, you will participate in a 1:1 interview conducted by Doris for approximately 1.5 to 2 hours. The interview will take place after work hours in a private setting off the unit at Toronto General Hospital. During the interview, you will be asked demographic information in relation to age, sex, education, experience (work and personal death experiences), and spiritual or religious affirmation. The interview will center on your experiences (e.g. thoughts, actions, challenges, observations, feelings, etc.) in working with patients diagnosed with cancer and who, therefore, experience having a life-threatening illness. You will be asked to think of stories about your work (past, present) at which time a patient(s) expressed some fears or feelings about his/her prognosis or potential end of life or where you observed that a patient was trying to deal with such issues. Your interview will be tape-
recorded and transcribed verbatim. You may be asked for a second interview to further clarify questions about your experiences or if there is a need to follow-up on ambiguity in interpreting transcribed data in the first interview. The observation and interviews will take place over a period of 4 to 6 months.

Participation in this study may cause some inconvenience to you, requiring you schedule time to meet for an interview(s) during times you are not working on the unit. A one-time stipend of $50.00 will be given to each nurse participant for interviews that will take place during non-working hours before or after a regularly-scheduled work shift. In addition, a coffee coupon from Tim Hortons is given in appreciation for your participation.

**Potential Risks and Benefits**
There are some potential risks and benefits to you by participating in this research. A risk may include emotional reactions given you are asked to reflect (in interviews) on challenging as well as rewarding experiences of being with patients who may have died due to treatment-induced complications or the seriousness of their illness. Additionally you may feel uncomfortable being observed in your practice.

To address these risks, the following steps will be taken:
1) The researcher as interviewer will offer opportunity at any time to pause, stop, re-schedule, or withdraw from the interview.
2) The researcher will be sensitive about your emotional responses and offer support and opportunity to discuss any concerns during and at the end of the interview(s), or at any time during observations.
3) Referral to supportive counseling will be discussed and made available to you if you choose, through the Research Student and her supervisor, Dr. Esplen. All information shared during the interview(s) will be strictly held confidential.

While there will be no direct benefit to you in participating in this study, you will be adding new understanding to an area where little information is known about how nurses learn, cope, and communicate skills related to supportive oncology care. Potential benefits of your participation also include the opportunity for you to voice feelings (often not shared) about meanings given to your work.

**Compensation**
As a way to compensate you for any inconvenience related to your participation, you will be given financial compensation (i.e., $50.00) to complete the interviews during non-scheduled working hours with the researcher. All field observations will be conducted during your scheduled work hours.

**Confidentiality**
All information collected during the study will remain strictly confidential. You will be identified only with a pseudo name. No names or identifying information will be used in any publication or presentations. No information identifying you or the ways you may express yourself will be communicated to any personnel in PMH or outside the hospital. The Research Student and her supervisor have no relationship to any staff of the BMT unit at PMH.

Privacy and confidentiality of the data will be protected through secure transport of all information and storage. All data with identifiers will be kept in a locked filing cabinet, in a locked office at UHN. This includes consent forms and audiotapes. Single identifiers are minimized and will be coded to enhance confidentiality. The legend related to the coded data...
elements will be kept only on the UHN secure server. All other data (i.e., transcripts and computer data) will not contain any identifiers and will be kept in a locked cabinet or password protected on a desktop computer in the locked doctoral offices of the Faculty of Nursing, U. of T. This data will contain only your study identification number and your pseudo name.

**Voluntary Participation**

Your participation in this study is voluntary. You may refuse to answer any questions you do not want to answer, by simply saying "pass." The process of consent is explained by the student researcher to ensure reasonable understanding of what is involved when consenting to the study. After 72 hours, you are asked to provide informed consent to a research assistant, Nicole Taylor. Please note that she is *not* directly involved in the study to avoid any sense of coercion.

As part of the ongoing consent process, you can choose not to participate or you may withdraw at any time without any explanation or any penalty. If you do withdraw from the study your data will be used only if you give your permission. Your time and travel to attend the interview session is still respectively paid.

**Researcher’s Relationship with Participants**

The researcher may have a relationship to potential participants as a doctoral student being advised by Dr. Doris Howell, the RBC Financial Group Chair in Oncology Nursing Research at PMH. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken: Participants' identities will be kept confidential and anonymous to the research advisory team (i.e., no names or identifying data will be shared with the advisory committee members). Only the principal investigator (Dr. Esplen) and the Student Researcher (Ms. Leung) will have access to demographic data and participants' actual names.

**Dissemination of Results**

It is anticipated that the results of this study will be shared with others in the following ways: illustrative examples for teaching, publication in the dissertation, publications, and presentations at scholarly conferences or meetings related to the substantive topic. To ensure confidentiality of participants, results will emphasize a thematic group analysis and only pseudo names will be used in excerpts of any exemplar accounts.

**Disposal of Data**

Data from this study will be shredded seven years after the study is published.

**Questions**

If you have any questions about this study you may contact the researcher, Ms. Doris Leung at [doris.leung@utoronto.ca](mailto:doris.leung@utoronto.ca) or phone at: [647-588-3623](tel:+16475883623). For further questions, her supervisor, Dr. Mary Jane Esplen may be contacted at [mesplen@uhnres.utoronto.ca](mailto:mesplen@uhnres.utoronto.ca) or [416-340-3024](tel:+14163403024).

If you have any questions about your rights as a research participant, please call Dr. [R. Heslegrave](mailto:rcheslegrave@uhnres.utoronto.ca), Chair of the [University Health Network Research Ethics Board](mailto:research@uhn.ca) at [416-340-4557](tel:+14163404557). This person is not involved with the research project in any way and calling him will not affect your participation in the study.

**Consent**

I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study with the understanding I may withdraw at any
time. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

Study Subject’s Name (Please Print) Study Subject’s Signature Date

I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

Name of Person Signature Date

Obtaining Consent

Please provide a ✓ to indicate whether or not you are willing to be tape-recorded during the interviews.

Please indicate if you wish to receive a copy of the final report. NO YES
If so, please send it to: ________________________________.

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix F

Descriptive Questions Guiding Field Observations

Descriptive questions will follow a narrative inquiry framework by Clandinin and Connelly (2000) (as cited by Ollerenshaw & Creswell's, 2002): Interaction, continuity or temporality, and situation or place. This will be added to Benner's (1996) ideas to re-interpret nurses' stories using different focal points relevant to constructing practice, particularly qualitative distinctions of practice and agency that guide clinical grasp of responsibilities, embodied know-how, agency and structure of practice.

<table>
<thead>
<tr>
<th>Situation/Place</th>
<th>Interaction</th>
<th>Continuity/ Temporality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Where are exchanges about patient care occurring?</td>
<td>Personal</td>
<td>Social</td>
</tr>
<tr>
<td>Where and how does talk about prognosis or decisions governing end of life occur?</td>
<td>What topics do nurses talk about or ask of each other?</td>
<td>What disciplines are represented in discussions about prognosis?</td>
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<td></td>
<td>How do nurses emotionally respond if a patient dies?</td>
<td>What is the group processes like when a patient dies? (i.e., who leads the conversation, who is silent, who contributes to the discussion and how)</td>
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<td>Is the death of a patient mentioned, and if so, how?</td>
<td>How do nurses talk about past experiences around issues of dying or death?</td>
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<td>What communication occurs related to patients' prognosis and fears of an uncertain future?</td>
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<td>What do nurses talk about trying to aspire to do in their work?</td>
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<td>What are the unexpected situations that nurses find jarring?</td>
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Appendix G
Demographic Data for Nurse Participants

Study Number __________________ Pseudonym:____________________

Number of Years Nursing Experience:_______

Number of Years Oncology Experience: _________

Other Nursing Experience: Please indicate:_______________________________________

Number of Years on this unit: __________

Age (Years): ________

Sex: 1. F _____ 2. M_________

Education:
1. Diploma _____
2. Baccalaureate __________
3. Masters Degree________
4. Oncology Nursing Specialty Certification: _________
5. Palliative Care Education: ____________________________

Spiritual or religious affiliation:___________________________________________________

Have you experienced a death in your personal life? No_____ Yes___ ; Was the person close to you? No_____ Yes____

If so, please indicate the relationship and the year death occurred, and the cause of death:
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
_____________________________________________________________________________

Any additional comments:
Appendix H
Interview Script of Topics & Questions for Nurses

Facilitator:
Welcome participant.

Explain Parameters
• Introduce self and study. Reinforce process of voluntary consent and parameters of participation.
• State boundaries:
  o "Anything said in this interview will be held in confidence."
  o "To engage in understanding your experience through your stories of caring, so that it is not a formalized question and answer interview but one that will evolve during our interview."
  o Ask for consent to tape record session.

Explain Purpose
To spend the next 90 to 120 minutes exploring who you are as an oncology nurse, how you understand your work in caring for people on the hematology oncology unit, and what it is like to care for people who are facing an uncertain future and perhaps, dying.

This interview will primarily be about recalling and telling stories.

B. Opening questions relate to obtaining demographic data (See Appendix G)
• e.g. What is your name and how long you have worked as a nurse in oncology?

C.

D. Introductory questions:
• What is it like for you to care for patients on this bone marrow transplant unit? OR
• How do you feel about your work with patients on this unit?

E. Transition to key topic areas:

F. You work in a hematology unit where patients often face uncertainty and thoughts about dying or they question their future or their prognosis.
Can you describe an experience of a particular patient who indicated to you that he/she had concerns about their future or dying? Can you describe what happened and how you responded?

OR

While shadowing you on the unit, I noticed.....OR During shift exchange reports, I've noticed.......(revealing comfort/discomfort) when discussing issues of prognosis, dying, or issues about death.

Can you tell me how you experience being with patients who often suffer fears of uncertainty about their future or fears of dying?

G. Examples of key questions (prompters or probes) for topic areas:
NOTE: Questions will be used as prompts when needing to focus the interview to substantive area and therefore may not be followed or given in the order presented here. Rather, the questioning will follow ideas in participants' narratives and asked to clarify or elaborate further on specific areas of interest using questions below:

• What were you feeling and thinking about as it was taking place?
• What did you say to do? How did the patient respond?
• What if anything, did you find difficult about the situation?
• How did you feel about what you did for the patient?
• What do you wish you could do differently in the care you give, if anything at all?
• In the days following the event, did you have any change in feelings or additional thoughts?
• What was particularly important to you about the experience?
• How did it compare to past experiences?
• How many years prior to this had you worked with similar patients?
• Did you discuss this patient experience with anyone later? If so, who, where, and when? (e.g. nurse colleague? friend? family?)

**Facilitator:** Summarize some of the salient feelings and experiences participant described from the interview.

• What was it like for you to talk about your experience(s)?
• How are you feeling about your experience(s) now compared to before the interview?

**Final question:**

• Is there anything else you would like me to know, or to tell me?

**Ending:** If you think about something you would like to add to this interview, please do not hesitate to contact me. Thank you for sharing your experiences with me.


Appendix I

Transcription Guidelines

Although transcription services will be employed to follow notation guidelines, a number of strategies suggested by Poland (2003) are used to enhance the quality of rigour in transcription.

1. Tape quality: Recording in a quiet place free from interruptions and asking the participant to speak clearly
2. Notation system and conventions for standardized syntax of transcription: See below.
3. Reviewing the quality of transcription: The researcher will read transcription alongside audio-recording of interview to check for discrepancies.
4. *Member checks of transcribed data at the discretion of the researcher, if there is a need to follow-up on ambiguity in the interviews: Avoid tidying up verbatim quotes till after participants can respond to any ambiguity to avoid altering meanings. (* only as needed on a case by case basis)
5. Use of corroborating evidence (fieldnotes) in the interpretation of context, especially with difficult passages to interpret.
6. Reporting on transcription quality in dissemination of research findings.

Transcription Notation System Oriented to Selective Syntax of Conversation

Transcription needs to follow audio-taped words verbatim of the interview (that is, do not edit or otherwise "tidy up" to make them sound better) and give attention to:

| 1. silences or pauses | (...) | Bracket indicates silence with number of dots in parenthesis to indicate approx. elapsed time in tenths of a second. Not more than one-tenth of a second.
| 2. inaudible word(s) | (x) (xxx xxx xxx) | Empty parentheses indicate the transcriber's inability to hear what was said. Use x's to denote approximate number of words that cannot be deciphered.
| 3. possible word heard | (word?) e.g. "At that moment he (doubled?) over" Parenthesize words are possible hearings.
| 4. louder emphasis of word(s) | WORD e.g. "He did WHAT?" capital indicate louder words, given emphasis, relative to previous talk
| 5. other non-verbal sounds, such as laughter or coughing | ((laughter)) ((coughs)) ((sighs)) ((sneezes)) transcriber's description of non-verbal sounds in parentheses
| 6. interruptions | - e.g. "What do you-" Indicate when someone's speech is broken off midsentence by including a hyphen at the point where the interruption occurs
| 7. overlapping speech | -(overlapping) e.g. R: He said that was impossible I: (overlapping) Who, Bob? Use a hyphen to indicate when one speaker interjects into the speech of another, include the speech of the other with "(overlapping)" then return to where the original speaker was interrupted (if she/he continues)

Sequence and types of field notes

Field notes will describe the lived experiences and circumstances of participants. The field notes follow four different kinds of conventions as discussed by Silverman (2000) on the timing and kinds of field notes needed. The proposed study will follow this sequence of notation during interviews and observations:

1. **The condensed account.** Brief notes will be taken during interviews and immediately following interactions with participants. These jottings will summarize the interviewers’ point-form observations of what actually occurred during the meetings. They will include phrases, single words, and unconnected ideas, and will be digitally recorded and then handwritten.

2. **The expanded account.** As soon as possible (ideally within 24 hours) after making the condensed account, the primary researcher will add details to the condensed version. These notes will be recorded using a word processor so they can be attached to the appropriate interview (transcribed) and entered into computer software as data. The condensed notes will serve as reminders to the writer, who will then add as many details as can be remembered.

3. **A fieldwork journal.** This is a reflexive log of the primary researcher's experiences and thought processes during data collection. It includes reactions to the interviews and interactions with participants. The journal also serves as a progressive account of the researcher's emerging understandings of the field. These reflections will be discussed with the doctoral student's supervisor and in regular advisory team meetings to help crystallize analytic ideas.

4. **Provisional Record of Analysis and Interpretation.** This analytic log or audit trail will be a provisional running record of general impressions of the data and the unfolding investigation, ideas about meanings encountered in review of transcripts, emerging interpretations of the field work, and insights into differences in participants' circumstances, problem engagement, emotional involvement, and their reasoned action. It will also serve as a record of ideas generated during supervisory and advisory team meetings.

## List of Nurse Participant Names, Study Numbers, & Pseudonyms

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<thead>
<tr>
<th>Study No.</th>
<th>Name</th>
<th>Pseudonym</th>
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Appendix L

Photographs of Artwork on Inpatient Units
Permission given by Institutional Organization
PEARLS IN THE MUCK
mural quilted by participants in the Tenth Annual Open House
hosted by members of the
and Marrow Transplant Peer Support Group
June 26, 2001 at
Appendix M

Fighting cancer while preparing for the possibility of letting go
(main common theme and 4 sub-themes)

Working within the Culture of Cure and the Possibilities of Patients Dying
- Understanding the Possibilities of Patients Dying
  - The culture of cure
  - Challenges Encountered in Recognizing the Possibilities of Patients Dying
- Watching over patients’ bubble of hope
- Reluctance to burst the bubble of hope

Concern about “bursting the bubble of hope”
- Recognizing patterns of dying
- Emotional attunement to fight or to let go
- Situated knowledge, capacity, and perceived control to instill the patients’ fight or to let go

Whether to & how to respond to patients’ distress and dying
- Communication about the threat of mortality & death
- Letting be & supporting families to let go
- Managing technology & preventing technological intrusions to patients
- Striving for patients to have easier deaths

Coping with patient involvement
- Acknowledging the threat of one’s own mortality
- Avoiding or detaching self from patient involvement
- Releasing tension created by nurses’ conflicting concerns
- Tempering patient involvement
  - Striving for patients to have easier deaths