SHARING MORTAL TIME:

TOWARD EVIDENCE-BASED UNDERSTANDING OF THE ROLE OF NURSING IN TRANSITIONAL CANCER CARE

by

Laurie Roberta Read

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the requirements for the Degree of

MASTER OF NURSING

Faculty of Nursing
University Manitoba
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THE UNIVERSITY OF MANITOBA

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DEDICATION

To Jim, my soul mate and inspiration, for all your love and practical supports, I dedicate this work.

It is given as in memory of our two parents, Florence Gray and J. Edward Read, who taught us so much in their living and also in their journey through mortal time.

For our living parents, Reginald Gray and Doris Read, we continue to experience the blessings of loving support and wisdom. Perseverance, integrity, and faithfulness are lessons you continue to inspire me with.

This work is also dedicated to my three children, Jeremy, Rebecca, and Philip, and their chosen life partners, Kristen, Kevin and Aimee. We have had the excitement of sharing weddings as well as studies. You have loved and supported me in each of your unique ways, and I feel blessed. For the very special gift of Ceanray, my granddaughter, who has kept me rooted in real life and exceptional joy in these first three years of your life, this work is dedicated to your potential and the acknowledgement that mortal time experience is also about the gift of new beginnings.

ABSTRACT

Nursing is challenged to provide better understanding of its role in caring for individuals whose treatment is no longer focused on cure. That quality of nursing affects patient quality of life is known; but the role of outpatient cancer care nurses in facilitating transition through timely identification of patient readiness for discussions about palliative care has not been researched. Experiencing illness progression is challenging and complex. Transition can cause tremendous angst for both patient *and* care provider. Insight, sensitivity, and skill are involved in broaching this "mortal time" (McQuellon & Cowan, 2000). Tensions arise in discerning "best practice" about when, how, by whom and what should be said.

Explanatory models (EM, Kleinman, 1992) served as the theoretical framework for this exploratory, descriptive qualitative study. Transition theory was explored as a contributing conceptual framework. The design comprised person-centered interviewing of a purposive sample of 7 peer-designated expert nurses and two focus groups (n=6) of self-selected nurses in a Canadian tertiary cancer care centre. Findings contribute to an understanding of nurses' work in outpatient cancer care.

Six themes emerged from the qualitative content analysis of verbatim transcripts: presencing and respecting personhood; discerning readiness: broaching issues of mortal time; preparing for mortal time; sharing mortal time: processing and facilitating awareness; doing the right thing right; and reflecting on mortal time: nurses' stories of personal and professional vulnerability and maturation. Implications for practice, education and research are discussed.

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To the nurses who so articulately shared the gifts of their experiences, wisdom, quandaries and compassion, I thank you. I have been honoured as you invited me into your narratives. My hope is to be able to share some of that personal learning with other nurses who are deserving of your collective wisdom and expertise.

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To all those individuals in my place of employment at the Salvation Army Grace General Hospital, and others in the community of cancer care provision who have encouraged me in the journey and affirmed the importance of the inquiry, I am grateful.

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And finally, I am grateful to the following contributors to my financial support during the Master of Nursing Program:

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CHAPTER ONE

STATEMENT OF THE PROBLEM

Introduction

Chapter One begins with an overview of the underlying issues that provide the rationale for this study, which explores and describes the role and experiences of expert nurses in transitional cancer care. Transitional cancer care is that period of time in the trajectory of care in which individuals—and their families—are living with progressing cancer for which the hope for a medically-defined cure is no longer deemed possible. Concepts that are salient to the study questions are discussed and defined. Assumptions inherent to the shaping of the research are also identified and described.

Background to the problem

Individuals living with metastatic cancer eventually experience transition from treatment with a focus on stabilization, even remission, of their disease to treatment with a focus on palliation, or the amelioration of suffering that enhances quality of life through comfort care.

In the field one can hear experienced cancer care nurses say, "I don't think this patient (and/or her family) is quite ready yet to have discussion about palliative care services or resuscitation issues." Or they may say, "He needs to have time to settle personal affairs—and I think by something he said the other day in expressing concern for his wife—that he is 'coming around the corner.' He may be more receptive now."

Experience that may be difficult to articulate may have influenced such comments. Perhaps nurses have had the experience of feeling the reassurance that they have made the "right" decision in broaching related issues because the individual living with progressing cancer (ILWPC) has expressed gratitude for 'laying the cards out on the table.' They may also have experienced feeling saddened, angry, ineffective, frustrated, or guilty because they have missed or misread cues of receptivity to talk surrounding preparation for death.

Understanding what is happening for patients as they respond to illness progression is challenging and complex. For most patients, their families, and their professional care providers, a clear-cut transition to a palliative care focus of treatment is rare. Ensuing responses to the experiences of chronic or rapidly advancing disease, along with necessary decisions about treatment and personal and spiritual affairs, can cause tremendous angst for both patient *and* care provider (Jeffrey, 1995; McQuellon & Cowan, 2000). Insight, sensitivity, and skill are involved in broaching the issues of this "mortal time," defined by McQuellon and Cowan (2000) as the psychological state human beings enter when confronted, either directly or vicariously, with the prospect of death. The profoundly subjective nature of this experience, and how influential the uniqueness of personal history and the person's "assumptive world" (p.313) is to the interpretive meaning of the experience of "mortal time," has been noted by the authors. McQuellon and Cowan (2000) discuss the complexity and risk of living in "mortal time," and what it means to authentically converse in this "space." They emphasize how sharing this sacred time can enhance coping and enrich meaning for those who turn toward death together. (The term "mortal time" as described and defined by McQuellon and Cowan has been a helpful concept in describing a complex phenomenon, and is used throughout this study report.) Participants in care decision making are beginning to realize how much *more* we need to do to facilitate such end-of-life discussions while patients with advancing illness are still well enough to contribute to the process.

Intuition, common sense and anecdotal experience tell most people that individuals who have benefited from timely discussion of end-of-life issues from a holistic perspective experience improved quality of life, and for the most part are better prepared to live until they die. Research is informing us even more about what factors patients, families, physicians, nurses and other care providers consider important at end of life (e.g., Carline, Curtis, Wenrich, Shannon, Ambrozy, & Ramsey, 2003; Chochinov, 2002; Chochinov, Hack, McClement, Kristjanson & Harlos, 2002; Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2002; Cohen & Mount, 1992; Degner & Beaton, 1987; Gregory & Russell, 1999; Hull, 1989; Kristjanson, McPhee, Pickstock, Wilson, Oldham, & Martin, 2001; Kuhl, 2002; Mayer, 1998; McClement & Degner, 1995; Papadimitriou, Argyrou, & Palegianni, 1998; Penson, 2000; Robertson, 2000; Steinhauser, Christakis, Clipp, McNeilly, McIntyre & Tulsky, 2000; Tefs, 2002). Furthermore, social families and professional caregivers of individuals who are dying also are able to process the experience of "mortal time" in a healthier manner because they are left with fewer regrets and can feel privileged to have been a part of something of deep personal value.

Purpose of the study

The purpose of this exploratory, descriptive qualitative research project is to articulate what happens in outpatient cancer care, where ongoing interaction occurs between expert nurses and individuals (patients) who are transitioning with their cancer care from curative to palliative treatment goals. The focus of the investigation is to explore with expert registered nurses how they discern patient and family readiness and openness to discuss relevant concerns in this transition, and to have them describe the experience of turning towards death together with ILWPC. It is commonly believed by many health care practitioners in cancer care that such discernment can enhance timeliness of supportive intervention and thus contribute to optimal quality of life as individuals live with the knowledge of their dying (e.g., Jeffrey, 1995; Norton & Bowers, 2001; Ronaldson & Devery, 2001; Schultz, 1999; Strauch, 2003). Meleis (1997) points out the importance of nursing theory development and articulation of nursing knowledge in the area of transitional phenomena because of the comprehensive approach (i.e., an integrated "biopsychosociocultural" perspective) nurses use in their interactions with people and the community of concern (p. 109).

Issues touched on in the exploration of their work included research questions (please see Appendix A: Interview guide) about the nurses' understanding of:

- the current referral processes for palliative care services
- determining patient readiness to deal with talk that reflects patient awareness of their death
- how they go about deciding to initiate conversation about palliative care, and what barriers or constraints they experience in that approach
- how they describe the experience of patients in transition from curative care goals to palliative care, with invitation to tell the stories of times when

transition did/did not go well and what factors they thought were influencing those outcomes

- how they prepare themselves for the interaction with the patient and/or family
- how they interact with other members of the health care provider team
- how they mentor newer members to cancer nursing, especially transitional care
- what their experiences are personally in relation to dealing with the impact of the work of transition; what self care practices they use; and, what they recommend for newer nurses in the field of cancer care nursing.

The more complex global research question of role delineation was examined by ascertaining particular aspects of the nurses' work through use of the probes in the interview guide. Their stories sometimes led them into areas not defined specifically by the primary question, but that were significant to illuminating the overall goal of exploring their role in transitional cancer care.

Key terms

It is evident that there is a lack of consensus, in both clinical practice and the literature, regarding conceptual definitions of key terms relevant to this study. These include "palliative care," "hospice care," "quality-of-life," "transition," "readiness," "social family," "expert," and "evidence-based nursing practice." In an effort to settle semantics at least for the purpose of this study the following background and definitions are provided. (Some of these terms were further illuminated by the findings, and those additional perspectives, including a model of transitional cancer care, are discussed in

Chapters Four and Five.)

Palliative care

Palliative care and hospice care have long shared historical roots, reflecting a focus on the relief of total suffering, with an intent to provide comfort rather than cure. The Oxford Canadian Dictionary (1998) states that to palliate is "to alleviate, mitigate (disease or its symptoms) without curing it." In the 1960s when Dame Cicely Saunders was contributing to formative development of hospice services, there was strong association with care when the end of life was imminent. In reviewing the expansive years of St. Christopher's Hospice, founded by Dame Cicely Saunders in 1967, Clark (2002) notes the expanding use of the terms "active," "palliative," and "terminal" care to denote a transferability of care regardless of setting (p.129), and an overlapping of services. In a letter sharing thoughts about starting a new hospice, Saunders suggests ways in which the vision and service of hospice was needing to expand (p.142). However, limited association of palliative/ hospice care with imminent end of life persisted for several decades, and has been reiterated by Pickett, Cooley, and Gordon (1998) in their discourse on past, present, and future perspectives of palliative care (p.86). Several authors note a trend to modify the definition. The trend of current thinking defines palliative care service according to need rather than according to a strict definition of life expectancy (Dudgeon, Raubertas, Doerner, Doerner, O'Connor, Tobin, & Rosenthal, 1995, p.5; Pickett, Cooley, & Gordon, 1998, pp.86, 92). Inherent to this description is the acknowledgement that supportive or transitional care is an expression of palliation within the continuum of cancer care. Some urge that palliative care should start with diagnosis of an initial recurrence (Dudgeon et al., 1995; Pickett et al., 1998);

and, others urge concurrent rather than sequential focus to oncological treatment and palliative care (Bausewein & Hartenstein, 2000; Periera, 2002). A study by Payne Sheldon, Jarrett, Large, Smith, Davis,Turner, and George, (2002) describes the confusion in England about the lack of definitional consensus and ambivalence about referral processes. They are not alone.

The government report of the Canadian Senate Subcommittee to update Of Life and Death (2000)—a report on the right of every Canadian to have access to quality end-of-life care—also notes that witnesses repeatedly indicated the need for end-of-life care services to be extended both in terms of diseases covered and the period of time for which they are provided (p.12). The concept of palliative care that underpins these arguments for introducing palliative care earlier in the illness trajectory will be incorporated into the intent of the term "palliative" for the purpose of this study as it fits well with the outpatient setting for transitional cancer care. However, the assumption prior to the research interviews in this study was that nurses should consider individual patient readiness for a discussion about the use of palliative care so defined prior to it being offered as an option for care focus. (Chapters Four and Five point out some variance to the practice application and understanding of this assumption.)

A systematic review done by Critchley, Jadad, Taniguchi, Woods, Stevens, Reyno, and Whelan (1999) identifies another trend. In addition to the traditional association with cancer care, palliative care has become more comprehensive and now encompasses patients with numerous chronic debilitating illnesses (p.40). This is a respected perspective; however, this study is focused on nurses in relationship with individuals with cancer because the outpatient setting for treatment is well-established and cancer care nursing is a certified specialty in both the USA and Canada. Furthermore, cancer is a disease for which there are always increasing treatment options for intervention in advanced disease and for which many clinical trials are designed. In this context of an explosion of interventions aimed at either cure or keeping the cancer "at bay," there is need for clear understanding of palliative care as one of the "treatment" goals professionals in cancer care offer patients and their families.

Though the terms "hospice" and "palliative care" are generally used interchangeably in the Canadian setting, that may not be true of all countries or settings. Nonetheless, the definitions accepted by the Canadian Hospice Palliative Care Association (CHPCA, 2001), The World Health Organization (WHO, 1990; 2002), The National Hospice Organization (NHO Guidelines, 1996) and the Education for Physicians in End-of-life Care (EPEC project, 1999) initiative in the USA, all share core elements. Given the contextual understanding of the discussion in this section, and for the purpose of a summative definition, the following list of core dimensions will be used to delineate intended meaning for the term "palliative care" for this study. Palliative care of the individual known to be living with a life-threatening illness intends that there is:

- inclusion of social family as part of the focus of care
- inclusivity for individuals of any age, of any diagnosis, with any prognosis, at any time that they have unmet expectations and /or needs and are prepared to accept care
- mitigation of suffering and improved quality of living and dying from a holistic perspective (i.e., physical, emotional, psychosocial, spiritual) with practical and informational needs and expectations being addressed

- acknowledgement of care goals no longer being curative (i.e., care may complement and enhance disease-modifying therapy, including the use of treatments and investigations needed to better understand and manage distressing clinical complications; or, palliation may become the total focus of care)
- provision of integrated, skilled, interdisciplinary care
- attention to affirmation of living until death, with focus on quality of life rather than prolongation of life efforts to coordinate funded and voluntary care across the continuum of possible services from hospital- based care through to supportive care in the home
- preparation for, and management of self-determined life closure
- attention to the experience of loss, grief and bereavement, including that which is anticipatory for patient and family, and not exclusively limited to family needs after death of the dying individual.

Hospice care

Hospice comes from the Latin word *hospitium,* a place of rest, and came to be understood as a home for the destitute or sick (Oxford Canadian Dictionary, 1998). It is often considered to be the original reference to care now also known as "palliative care." Historically it was a term associated with care for the sick and destitute, derived from the Christian tradition based on the 'good Samaritan' principle that we are our brother's keeper, and popularized in the fourth century A.D. when the monk Fabiola established a hospice in pagan Rome for Christian pilgrims from Africa (Ley & van Bommel, 1994). Thus, for some people hospice was linked with socio-economic status and being needy.

Dr. Paul Henteleff (personal communication, 2002), one of the pioneer physicians of palliative care and hospice in Canada, has given this perceived negative connotation as influencing the historical reason in Canada for a move in Quebec to the preferred use of the term "palliative care." (Clark (2002) confirms that Balfour Mount, a physician at the Royal Victoria General Hospital in Montreal, began to popularize the term "palliative care" in 1975 (plate 28)). Yet now in Canada and in many parts of the world the term "hospice" is used interchangeably with "palliative care" and many associations (e.g., Hospice & Palliative Care Manitoba, Canadian Hospice & Palliative Care Association) incorporate both terms into their name (CHPCA, 2001; Doyle, MacDonald & Hanks, 1994, 1998; Dudgeon et al, 1995; Ley & van Bommel, 1994; Massarotto, Carter, MacLeod, & Donaldson, 2000; Victoria Hospice Society, 1993). One might also wonder if the move to the use of "palliative" care as the preferred term was a subtle shift reflecting the social construction of death and dying as medical, scientific approaches to care and the powerful role of physicians grew in societal influence. (Neil MacDonald has pointed out that with better treatment options that have come from clinical trials using new and combined cytotoxic agents "cancer came to be regarded as a disease of organ dysfunction rather than an illness—an illness with psychological and spiritual dimensions embracing both the patient and the patient's family and the community" (Doyle, Hanks, & MacDonald, 1998, p.11).) Dying and death increasingly happened not in the home but in hospitals, and it is still difficult for many people in society to recognize that "death is not a disease…and dying is not a clinical diagnosis" (Ley & van Bommel, 1994, p.31).

Hospice may be used by others to denote a setting, often a free-standing service, or comprehensive service focused on the care of individuals whose longevity health care practitioners estimate is less than six months (National Hospice Organization Services Guidelines and Definitions, 1996; Ronaldson & Devery, 2001). The CHPCA (2001) suggests that, though the terms are used interchangeably in Canada, *hospice care* is used by some "to describe care that is offered in the community rather than in hospitals," and may be more likely to have a higher component of volunteer staff (Ley & van Bommel, 1994). Bausewein and Hartenstein (2000) note that in Germany there is distinction between palliative care units (connected to hospitals and focused on complex symptom control) and hospices (general practice care of individuals who cannot remain at home but who do not need hospitalization) (p. 536). In some locations hospice care has come to be understood operationally within a stricter context of end-of-life care and/or less acuity of need for intervention. In these locations, palliation is perceived to be broader in scope and is often associated with earlier intervention for issues such as symptom management, or referral to support services in transitional care (Pickett, Cooley & Gordon, 1998). Thus, for the purposes of this study, hospice care will be understood to involve the same principles of care as outlined in the section defining those core elements of palliative care (see definition above); but, operationally will mean palliative care that is limited to what is believed to be the last 6-9 months of life.

Quality of life (QOL)

Public response to improved palliative care and the hospice movement has positively influenced the concept of quality of life as a major clinical endpoint in care of individuals living with cancer (Cohen & Mount, 1992; Morgan, 2000; Pickett, Cooley & Gordon, 1998). One of the greatest challenges, however, is to define what is meant by QOL in the context of cancer care and palliative care, as some ambiguity remains in the apparent absence of a common definition. To date there is no "gold standard" instrument to measure QOL—though Carr and Higginson (2001) note that some of the newer standardized measures may be more patient-centered and culturally sensitive than earlier measures, but that further research is still required. Numerous themes are, however, reflected in the literature; so some core ideas about quality of life as gleaned from that review will be used to help define QOL for this study (Anderson, 1994; Benoliel, 1987-88; Carr, Gibson & Robinson, 2001; Carr & Higginson, 2001; Calman, 1984; Cella, 1992,1994; Cella & Tulsky, 1990; Cella, et al., 1993; Cohen & Mount, 1992; Farsides & Dunlop, 2001; Ferrans, 1990a, 1990b; Ferrell, 1993, 1995; Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991; Ganz, 1994; Grant, Padilla, Ferrell et al., 1990; King, Haberman, Berry et al., 1997; MacDonald, 1992; Morgan, 2000; Ross, 1995; Schipper, 1992; Sneeuw, Aaronson, Sprangers, Detmar, Wever & Schornagel, 1999).

Life consists of physical, psychosocial, occupational, emotional, and spiritual domains which may or may not be integrated harmoniously, and individuals will make their own assessment about their state of health, performance status, and well-being within those domains, according to what they believe is possible or ideal. QOL is determined by "the extent to which an individual's hopes and expectations are matched and fulfilled by experience" (Calman, 1984, p.125). Other contextual factors, including the need for value systems, cultural and multilingual sensitivities, are reflected in measures such as the World Health Organization's QOL profile (WHOQOL-100, 1994). QOL literature in the early 1990's reflected some of the struggles between thinking such as that of Schipper (1990) who suggested delimitation of QOL to the physical, psychological and social response to a disease and its treatment, with a claim that dimensions such as religiosity, life satisfaction and ambition were too imprecise. He was challenged by Cohen and Mount (1992) who noted that to ignore such central parameters in measuring QOL in palliative care assessment, was to ignore the matters of suffering, and transience that were integral to one's sense of personhood and life meaning as one was faced with death. Concurrently, however, there was literature that reflected increasing consensus about the subjective, objective, and multidimensional nature of quality of life (Cella,1994; Cohen & Ferrans,1990). Ferrans (1990b) defines QOL as reflecting a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to herself or himself (p. 253).

QOL is also an interdisciplinary concept that provides opportunity for enhanced clinical care outcomes. Integral as the contributions of various professional disciplines are, it is the individual himself or herself who is at the center of the concept of quality of life. "Quality of life then is therefore defined by the individual" (Morgan, 2000, p.407), and represents the perspective of the patient in quantifiable terms (Ferrans, 1990a; Ferrell, Grant, Padilla, Vemuri, & Rhiner, 1991; Schipper, 1992). The CHPCA has affirmed this direction in the 2001 Norms of Practice for Hospice Palliative Care (Item 37, p.8). In discussion of the many available tools and how to select the most appropriate instrument, Pickett and co-investigators (1998) note that patient self-reporting is still the preferred method of measurement (p.88). But appropriate timing of use of measurement tools is another factor that Pickett et al. point out. Their directive underscores the assumption of this present research that timing for exploration and intervention related to use of such tools is critical in transitional care. This view is supported by the reminder that QOL is a dynamic state, and values and priorities change in response to life circumstances (Carr & Higginson, 2001; Cohen & Mount, 1992). Cohen and Mount (1992) poignantly conclude their discourse on the matter with the injunction that interactions of heart and mind in the deepest levels of human experience have never been easy to measure (p.45). It may also be fair to say that the deepest levels of human experience may not be amenable to intervention by health care providers.

For the purpose of this study, QOL will refer to the patient's self-reported dynamic state of well-being according to life's domains of satisfaction/dissatisfaction most important to him/herself in the context of current personal life circumstances.

Transition

Based on a review and synthesis of the nursing literature from 1986-1992, Schumacher and Meleis (1994) supported the claim that transition is a key concept in nursing (p.119). Meleis and Trangenstein (1994) described facilitation of transitions as a redefinition of the nursing mission, noting that nurses work with people who are anticipating, experiencing, or completing transitions. These may be developmental, situational, organizational, or health-illness events (Schumacher & Meleis, 1994, p.120), and involve change and processes of development, flow or movement from one state to another, over time (p.120). Bridges (1980) notes that internal processes usually accompany the process of transition (p.11). "How human beings cope with transition and how the environment affects that coping are fundamental questions for nursing. Nursing seeks to maximize clients' strengths, assets, and potentials...and to contribute to restoration...to optimal levels of health, function, comfort, and self-fulfillment" (Meleis, 1997, p.109). Other authors have used the term transition in conjunction with the need to adapt to the diagnosis of cancer and in reference to changing dimensions—such as completion of a treatment plan, altering treatment goals or modes of care, and recurrence—in the experience of cancer (Brennan, 2001; Blasco & Bayes, 1992; Clarke-Steffen, 1993; Webber, 1998). The notion of transition is certainly key to the research at hand. Significant themes from the literature will be used in this study to provide clarification of the concept of transition.

Transitions in life are associated with first indications that life as it has been known is about to change, evoking a sense of threat, or loss, or a perception of disconnectedness from the usual social network (Bridges, 1980; Chick & Meleis, 1986; Davies, Reimer, & Martens, 1990; Meleis, 1986; Webber, 1998), so that there is a "fracturing of reality" (Clarke-Steffen, 1993, p.288). In Bridges' (1980) words, transitions are "endings that begin with something going wrong" (p.109). Hill (1991) echoes this concept: "Many patients say that when they discovered a breast lump, or first heard the diagnosis of cancer they experienced an acute poignant awareness that life would never be the same" (p.106). It may also be noted that there are many life transitions that are developmental in nature (e.g., pregnancy, puberty, becoming a parent or spouse) and thus not necessarily be experienced in a negative context. This project, however, occurs within the understood context of transition associated with progressing illness because of cancer.

In their book Counseling Adults in Transition, Schlossberg, Waters, and Goodman (1995) define transition broadly as "any event, or non-event that results in changed relationships, routines, assumptions, and roles" (p.27). The impact of the facts, and realization of the true nature of the triggering event, forces the individual and social family members into a state of what has been described in a variety of ways. Bridges

(1980) discusses this stage of limbo as the "neutral zone," a term that seems at odds with the experience otherwise described throughout his book as one of emptiness, lostness, a time full of hurt, shame, distress, disorientation, confusion, chaos, disengagement, disidentification, disenchantment, and vulnerability. Arnold (1999) describes the completion of cancer treatment, another significant time of transition, as "a crisis precipitating a period of disequilibrium" (p.21), and describes how participants in her study expressed feelings such as fear (of recurrence), anxiety and uncertainty. Bridges does remind his readers that with endings there is "fertile emptiness" or quietness where new things can begin, but also that this part of the process must not be rushed, so that inner renewal and meaning–making can happen (p.120-131). Davies, Reimer and Martens (1990) use Bridge's framework to describe the nature of the transition of "fading away," noting the complexity of the paradox of living and dying at the same time (p.16).

Schematic drawings to depict transition have been used by numerous authors and groups. Some early models show clear demarcation between curative treatment, palliative care, death and follow-up bereavement care for others significant to the person who has died. Evolution of the rectangular figure then demonstrated acknowledgement that the time from diagnosis of recurrence or progressing illness was not always straightforward, so models began to use a broken angular line as can be seen in Figure 2.

Figure 1. Early model of palliative care

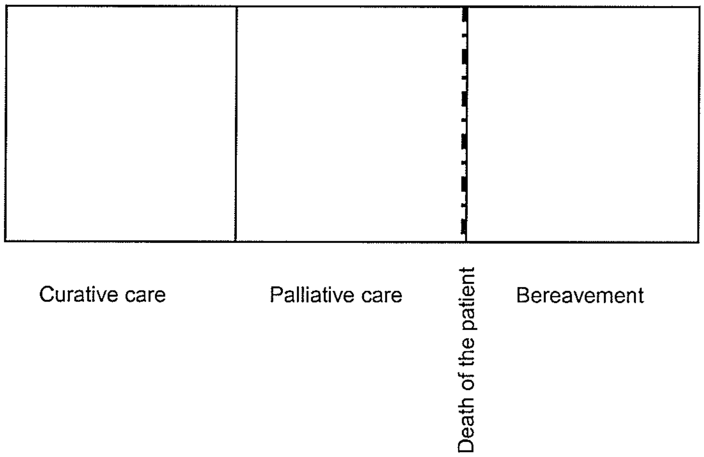
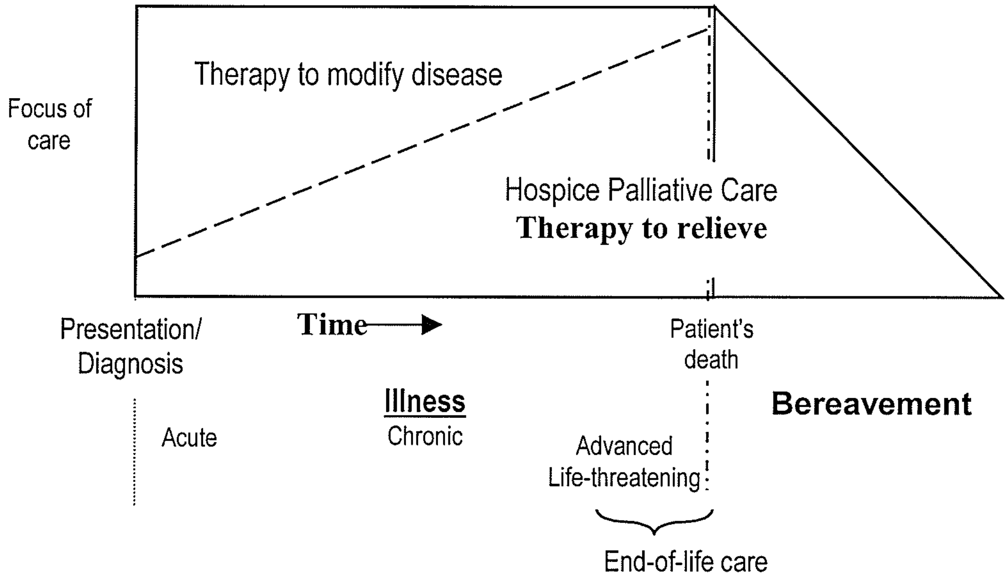


Figure 2. The role of hospice palliative care during illness



(CHPCA, A model to guide hospice palliative care, 2002)

Unfortunately, Figure 2 —which is currently used— does not fully capture two things. The period of transition in cancer care is not always so clearly demarcated, and in fact, may be better designated as an erratic, wavy line separating curative and palliative care foci. This is an important idea to consider if indeed palliative care is patient-centered and we heed the subjective experience of ILWPC as the narrative literature reflects. Furthermore, bereavement is typically drawn in as a box *following* death; but bereavement would better be represented if drawn as an overlapping presence in the paradoxical time of "living-while-dying" in order to acknowledge the losses that individuals experience as illness progresses. (Such thoughts were similarly presented by Jose Periera at the Hospice Palliative Care Conference in Winnipeg, Manitoba, September 18, 2002.) Anticipatory grief is experienced by both the ILWPC and his or her social family.

This study has attempted to think beyond a boxed figure of transitional cancer care, and the figure is offered as Appendix B. Others have also provided models depicting the individual in transition (Schlossberg, Waters & Goodman, 1995, p.27). Schumacher and Meleis (1994) provide a nursing model of transition indicating how nursing therapeutics (promotive, preventive and interventive) interact with the conditions, properties and types of transition to effect indicators of healthy transition (subjective well-being, mastery, and well-being of relationships) (p.125). Davies and Oberle (1990) also offer a model depicting dimensions of the nursing role in supportive care nursing (p.89). While each model has contributed much to the description of the lived experience of transition for the individual, and some for the nurse living the experience vicariously, none seem to capture the upheaval or troubling emotional impact that transitions have on people's lives while they work to either "adapt" (Blasco & Bayes, (1992) or "adjust" (Brennan, 2001) to them.

Sensitivity to the timeliness of supportive measures during this period can assist in the achievement of what Brennan (2001) describes as "positive transition" in which individuals discover a new sense of personal control, and an affirmation of the self through re-examination of their identity (p.11). Recognition of negative transition, including manifestation of poor self-image/self-worth, relational difficulties, depression, anxiety, worry and loss of personal control (p.11-12) is an important element of nursing assessment, and warrants intervention. From their review of the literature, Schumacher and Meleis (1994) identified some universal conditions that mediate transition, including meanings, expectations, new knowledge/skills (especially in relation to relief of uncertainty), environment, planning, and emotional and physical well-being. These authors, as well as Selder (1989), underscore the importance of awareness of the personal meaning of a transition from the patient's perspective.

Though focused in a different area of study, Mercer, Nichols and Doyle (1988) have provided transferable insights from their literature review on transitions over the life cycle. Transitions may be defined as turning points that lead to new self-conceptions through the assumptions of new roles, activities, and relationships, as well as inner life changes in outlook and self-definition. These authors also cite Elder (1985), who notes that the trajectories in which transitions are embedded, give them meaning (p.144). This is particularly applicable to the present research as facing reminders of one's own mortality on a constant basis adds to the complexity of progressing cancer. Meleis and Schumacher (1994) point out that because of the profundity of health-related effects on clients, there is a need to design nursing therapeutics that both prevent negative consequences and enhance positive health outcomes (p.125).

For the purpose of this study then, transition will be defined as a change in one's life as it has been known as a result of something going wrong—a developmental, situational and/or health-illness event—which evokes a sense of threat, angst, chaos, loss, and/or a perception of disconnectedness from the usual social network. Thus, over a period of time, relationships, routines, assumptions, and roles change in meaning; and, the outcome from contextual personal significance of that time period, may be perceived as a positive or negative "new beginning." The discussions in Chapters Four and Five will highlight a model of transition that has been developed as a result of the literature review in combination with the findings in order to depict the experience of nurses as they work alongside ILWPC.

Readiness

Fowler's (1998) concept analysis of readiness reveals a literature review that focuses on "readiness" in relation to preparedness to begin or accept a therapy or life style change. Examples provided included smoking cessation, dietary habit changes, or compliance with suggested treatments such as rehabilitative interventions. There is no mention in Fowler's analysis of readiness to correlate specifically such preparedness to the acceptance of hospice/palliative care treatment, intervention, or services referral; nor is there mention of the facilitation of transition towards end-of-life care. A literature review for this project also revealed absence of application to this area of health care or the illness trajectory. This study illuminates the concept of readiness in the context of approaching end of life at least to some degree. For the purpose of this study, the phrase "prepared to accept care" that is used in the CHPCA norms (2001, p.2) is linked with the intended meaning of "readiness" in this project. "Readiness" is also associated with the concept of an awareness of, and willingness to acknowledge "mortal time," as described by McQuellon and Cowan (2000). Descriptors from the study findings as discussed in Chapters Four and Five will further enhance understanding of the concept of readiness in this context of care.

Social family

For the purpose of this study, "social family" refers to those individuals who may or may not be related by birth but who are designated to mean "family" by the competent patient, or the proxy if the patient is not competent. Social family members may or may not be in the role of caregiver, but by virtue of some special relationship *are* considered by the patient to be an integral participant in the patient's decision making processes. McClement and Woodgate (1997) provide a comprehensive discussion on the topic of "family" designation, a discussion which reminds readers to be wary of making any assumptions about who may be thought of as "family" in the view of any individual receiving health care. The CHPCA (2001) Norms document reflects some of this awareness and shapes the definition by stating that the "patient defines who will be involved in his/her care;" that family refers to "those closest to the patient in knowledge, care and affection," and "may include the biological family, the family of acquisition (related by marriage or contract), and the family of choice and friends (including pets)" (Item 16, p.5). In summary, family is whoever the person says his or her family is. Wherever the terms "social family" or "family" are used then in this paper, the intent is to be as inclusive, culturally sensitive, and as patient-centered as possible.

Expert

Since the early 1980s nursing literature reflects a growing interest and debate about the definition of nursing expertise and exemplary nursing practice. Benner's (1984) seminal article, "From novice to expert," identified a nursing application of the DeVries model of skill acquisition and levels of competency that led to the identification of characteristics of expert nursing practice. Her work has led to much discussion in the literature, especially about the validity of intuitive aspects of nursing "knowing" and expertise (e.g., Agan, 1987; Benner, 1984; Benner & Wrubel, 1982; Benner & Tanner, 1987; Cash, 1995; Cioffi, 1997; Darbyshire, 1994; Eason and Wilcockson,1996; English, 1993; Farrington, 1993; Jasper, 1994; Miller, 1995; Paley, 1996; Perry, 1998; Rew & Barrow, 1987; Rew, 1990; Rolfe, 1997; Schraeder & Fischer, 1986).

Patricia Benner (1984) identified the following attributes of nurse experts:

- ability to make clinical judgments or manage complex situations in a truly remarkable way
- possessing a vision of what is possible in patient care situations
- having an intuitive grasp of each situation and being able to zero in on the accurate region of the problem without wasteful considerations of unfruitful alternative diagnoses and solutions.

In her view, "expert" performance draws on experience combined with intuition that is based on "deep background understanding" rather than "mysticism," capturing a holistic view of a situation in a discriminating manner that does not need to rely on rules or fractionated guidelines. Nor does expertise require detailed, rational reasoning processes in order to lead to sound, timely, and independent clinical decisions. Benner and Wrubel (1982) confirm the notion that expert human judgment reflects discernment that is irreducible to just objective measurement, but includes qualitative, perceptual and holistic perspectives. This view will be adopted in this project as integral to the meaning of "expert," in spite of debate (e.g., Cash, 1995; Correnti, 1992; Darbyshire, 1994; English, 1993; Farrington, 1993; Noyes, 1995) over Benner's (1982, 1984) emphasis on intuition as a hallmark of clinical expertise.

A review of the literature indicates there is some consensus about other characteristics that are generally associated with nursing "experts." A meta-analysis by Adams, Pelletier, Duffield, Nagy, Crisp, and Mitten-Lewis (1997) provides a comprehensive summary of these additional behaviors—a broad range of clinical skills and competencies—including:

- highly selective assessment techniques and management rationales
- advanced critical thinking
- superior decision-making and care coordination
- adaptation in complex changing contexts
- collaboration and negotiation ability
- transformative emotional and informational support for others.

Furthermore, an important piece of evidence related to this study is that nurse "experts" can actually shape optimal patient care outcomes (Adams et al., p.220). Such influence of exemplary nursing on patient care outcomes is reflected by Rolfe (1997) who observed: "By beginning to understand how 'experts' think, it might be possible to develop expertise in a more controlled and logical way, thereby improving the practice of nursing" (p.1070).

Based on this review of the literature, the designation of "experts" in this study refers to those nurses that are nominated by their peers because their exemplary practice reflects noteworthy qualities of advanced competency and holistic discernment in complex care situations.

"Evidence-based": a descriptor

The inclusion of the term "evidence-based" in the title of this study may lead to questions reflected in the current debate about whether or not nursing as a profession should embrace the tenets of evidence-based medicine, evidence-based practice, or evidence-based nursing. The idea of 'evidence-based *understanding*' captured in the title of this study is an attempt to bridge the potential rift that Jennings and Loan (2001) identify as a "rehash of the quantitative versus qualitative debate" (p.125). These authors note that what constitutes best evidence is essentially focused on two critical questions—"what constitutes legitimate sources of knowledge and what comprises acceptable research methods" (p.125).

The stance for this study reflects that of a number of authors. Nurses have long embraced multiple sources of knowledge (Carper, 1978). In the present debate, some argue that nursing evidence is about art as well as science; thus, the rules of evidence must include a variety of knowledge sources in addition to the focus on the results of randomized clinical trials (Closs & Cheater, 1999; Estabrooks, 1998; Goode & Piedalue, 1999; Ingersoll, 2000; Mitchell, 1997, 1999; White, 1995). In discussing evidence-based practice and nursing leadership, Stetler's group (1998) suggests that to base all practice on "science" (i.e., the findings of controlled experiments rather than the findings of clinical experience) is neither possible nor desirable. Conn, Burks, Rantz and Knudsen

(2002) base their description of evidence-based practice on the combined emphasis of evidence authority with clinical acumen. Ingersoll (2000) notes that application and discovery are different phases of nursing knowledge development, but *both* [my italics] are integral to scholarly processes (p.151).

Health care questions cover a broader scope than interventions and cause-effect relationships, and Jennings and Loan (2001) purport that "scope also encompasses issues of clinical effectiveness or whether interventions and encounters do more good than harm in everyday circumstances" (p.126). These authors ask some important questions about the potential silencing of evidence and subjective truth that comes from rigorous qualitative and descriptive research. Aranda's (2001) research, which explored nurse-patient relationships in cancer and palliative care settings, points out the need for nurses to learn to describe what it is they do under the rubric of caring. "Making these silenced aspects of practice visible helps us to use them in skilled rather than taken-for-granted ways to the benefit of patients and families" (p.183). She further suggests that "the closer we are to patients as people, the more likely we are to understand their feelings and responses to their experiences, and to be responsive to their needs" (p.183). "Somewhere between the extremes of distance and intimacy lies what many nurses 'know' but which remains largely undescribed" (p.184). Norton and Bowers (2001) agree, and their research has described a perspective of "this largely invisible work" (p.268) of care providers attempting to move patients and families towards a "good death." This need to better understand the capacity for nurses to make a difference to the lives of individuals who suffer with advancing cancer is of primary significance to this study.

In the context of vigorous debate about sources of "evidence," it is believed this research project brings new knowledge and furthers the understanding of the nurse's role in transitional cancer care. The following definition is used for the purpose of this study:

> Evidence-based nursing practice is the conscientious, explicit and judicious use of theory-derived, research-based information in making decisions about care delivery to individuals or groups of patients and in consideration of individual needs and preferences (Ingersoll, 2000, p. 152).

Assumptions

The following assumptions which underpin this study need to be acknowledged.

- It is assumed that a certain group of cancer care nurses have some advanced level of insight, expertise, knowledge and sensitivity in facilitating transitional cancer care for the purpose of improving the quality of the care for patient and family. This assumption is based on theory related to nursing expertise as well as anecdotal evidence, and is also supported by the literature (see the discussion of the definition of "expert," Chapter One, as well as the Literature Review, Chapter Two).
- It is recognized that nurses are not infallible, nor may all experienced cancer nurses be comfortable or skilled at getting at the issues that persons living with progressing cancer identify are important to them (see Literature Review, Chapter Two). For this reason, theoretical sampling by forming two focus groups with nurses of various levels of proficiency, according to their self-identification with one of Benner's (1982) defined levels of practice, along with individual interviews with peer-nominated "experts," was included in the study design. That complete fulfillment of this design element was not able to be realized to the extent desired is a limitation that is discussed in Chapters

Three and Five.

- Nurses may not consistently have all the contextual supports to foster satisfactory, empathic communication and other interventions to facilitate timely palliative care (e.g., Berwick, 1995; Brody, 1995; Curtin, 1996; Lo, 1995; Marshall, 1995; Pippy, 2001; Solomon, 1995).
- It is acknowledged that not all patients from a cultural or personal perspective want to know the truth; nor may they want to participate in decision making processes in general, related to treatments and services available to them (e.g., Biley, 1992; Ptacek & Eberhardt, 1996). It is assumed then that expert nurses will assess these patient preferences and wishes prior to broaching matters of palliative care and other end-of-life issues.
- Acceptance of a palliative/hospice care philosophy may not be desired by all patients; nor may all individuals living with progressive illness transition to a point of acceptance, "understanding the 'big picture'" (Norton & Bowers, 2001), or "open awareness" of their dying (Glaser & Strauss, 1965). This assumption stands in contrast to the premise of Norton and Bower's (2001) research in which they researched the purposeful shifting of treatment choices of patients from "unrealistic" to "realistic" according to the perception of the health care providers involved. However, this study's premise suggests that expert cancer care nurses are able to discern such patient wishes and honor them in keeping with the sensitizing concept of explanatory models (see Chapter Two). How nurses articulate their ability to discern that perspective and respond appropriately was one of the desired findings for this study.

In summary, this study's literature review (Chapter Two) and clinical perspectives provide some indicators that nurses in transitional cancer care have shared wisdom that helps to determine signs of patient readiness to talk about the ways in which they may find support as they consider their death.

Significance of the study

In their daily work, expert nurses respond almost intuitively to the needs of patients and families who are living with incurable cancer (Perry, 1998). Articulation of this "intuitive" process may lead to development of improved strategies for preparing both nurses and patients for the complexity of that interaction. The ultimate goal would be to potentially facilitate discussion of existential issues and other matters of meaning to individuals who are experiencing serious illness, earlier in its trajectory, during a time when persons are better able to participate in their own care planning. As Jeffrey (1995) indicated, patient autonomy is significant to this decision making; yet, Ronaldson and Devery (2001) have indicated from their study that often patients expressed feeling rushed (p.173-174) or were not even included in the decision-making process (p.174) that led to changes in their care provision. Effective communication and facilitation of patient autonomy in care planning for those who choose it, enhances quality of life for the cared-for, as well as for the family and professional caregivers (e.g. Emanuel, 1995; Hofmann, Wenger, Davis, Teno, Connors, Desbiens, Lynn & Phillips, 1997; Ptacek & Eberhardt, 1996; Singer, Martin, Lavery, Theil, Kelner, & Mendelssohn, 1998; Singer, Martin & Kelner, 1999). A better understanding of how and when nurses are sensitive to the nuanced readiness of patients and their families is an outcome of this project. (It is acknowledged that such readiness may not be in synchrony for the patient and individual family members.) It was projected that findings from this study then, could be beneficial in several applications, as described in the following sections.

Nursing practice

By articulating understanding of their practice in the study findings, nurse "experts" in the field of cancer care have the potential to encourage greater integration of their knowledge and experience in the role of mentoring peers, as well as others on the team of care providers. The findings, sensitized by the conceptual framework of explanatory models, will:

1) raise awareness of the complex nature of the role of nursing in transitional cancer as it interfaces with palliative care
2) demonstrate need for assessment of patient and family readiness for discussion about transition and palliative care issues
3) prepare a framework for development of interventions, care protocols, educational approaches, and policy formation that will then need to be researched in clinical setting application.

Improved QOL for patients, and quality of living for their families

As patients are "ready," they can appropriately be provided with timely access to both informational support and symptom management that both acknowledges and addresses relief of physical, psychosocial, and spiritual suffering. As able or as desired, ILWPC can actively participate in their care planning and treatment decision making, discuss advance health directives and other issues in a context not pressured by urgency in transfer of services, as so often happens in the environment of current health care systems. Improved quality of life, based on individuals' definition of well-being and what life domains of satisfaction are of importance for them, will then more consistently become an integral part of the goals in provision of transitional cancer care in the outpatient care setting.

Further research

Findings may stimulate further research in nursing and other disciplines that are involved in support of individuals with progressing cancer, as well as other progressing chronic illnesses. It will be imperative to follow up this research by further study of timeliness and support of end-of-life decision making from the perspective of the individuals who are the primary participants (that is, the ILWPC, and their families). We cannot assume that our professional understanding of readiness is congruent with theirs (Wilson, Dowling, Abdolell, & Tannock, 2000). Replication of the research in other settings, such as through community home care supports, will also need to be done to add to the comprehensiveness of the findings.

Nursing education

Nursing knowledge about the concepts of people's experiences of transitional care and their identifiable behaviors of "readiness" to transition is articulated and expanded as a result of the participants' sharing of their expert observations and stories. Methods of assessment and intervention are described and can be further developed for application to cancer care as well as possibly in other chronic illnesses. A focus on "expert" nursing behaviours in the area of transitional cancer care may illuminate gaps in education for nurses who do not perceive themselves to be comfortable or having a desired level of expertise in supporting transition of ILWPC towards death.

Improved quality of work life

Diminished moral distress and caregiver "burn-out" in the professionals involved (Jameton, 1993; Wakefield, 2000) may result from provision of timely and effective transitional care. The assumption here is that professionals who contribute positively to the process of the experience of "mortal time" (McQuellon & Cowan, 2000) are healthier because they are left with fewer regrets, less moral distress, and less accumulative grief. They can feel privileged to have been a part of something of deep personal value.

Community health

The overall sense of having appropriately managed timely and sensitive referral to informational and supportive palliative care services, diminishing psychosocial, spiritual and moral distress, and enhancing healthier experience of the innumerable losses for persons living with progressive cancer, their social families, and their professional care providers, has the potential to contribute to general community health.

Conclusion

The need to discover more about how and when nurses identify patient readiness, or how they facilitate transitional care so that people can access the support of palliative care services in a timely manner, was a need identified as requiring further study—a need so pressing that it has been frequently affirmed by health care providers and ILWPC alike in an anecdotal manner as this student broached the tasks of the research project. The potential positive significance of the study has also been identified. Terms inherent to the meaning of the study have been clarified to provide some measure of congruence in a complex set of phenomena. Chapter Two follows, providing description of the conceptual framework of explanatory models, and a discussion of related literature and research studies that further confirmed the need for this study. The foundation has been established for the choice of research design, as well as support for the derivation and intent of the research questions.

CHAPTER TWO

THE LITERATURE REVIEW

Introduction

A review of the literature and research concerning transitional cancer care issues (e.g., facilitation of access to palliative care, preparation of patients and families for end-of-life decision making) demonstrates a growing interest in improving current strategies for coping with this complex time. The review has broached the question of how and when nurses involved in the experience of entering "mortal time" (McQuellon & Cowan, 2000) do so now; and, how nurse-patient relationships at this transitional time of the illness trajectory are influenced by contextual factors. Complexities inherent to this sensitive time for all concerned are described and discussed with special focus given to the nursing role in the context of care relationships and socio-cultural environmental influences. The theoretical framework of explanatory models is outlined and its value in terms of this study explained. Several research studies related to the present study are reviewed, and comparisons made with the design of this research study to locate the usefulness of this project in contributing to improved knowledge of nurses' entering "mortal time" with individuals who are living with advanced cancer.

The nursing role in transitional cancer care and palliative care

Perceptions elicited from the recipients of care about nurse behaviors that are essential and supportive in order for patients and family members to feel cared for as they live with “mortal time” have been described in the literature (e.g., Barthow, 1997; Bottorff & Morse, 1994; Carline, Curtis, Wenrich, Shannon, Ambrozy, & Ramsey, 2003; Davies & Oberle, 1990; Davies, Reimer, & Martens, 1990; Kristjanson, McPhee, Pickstock, Wilson, Oldham & Martin, 2001; Larson, 1984; Larson, 1986; Raudonis, 1993; Sapir, Catane, Kaufman, Isacson, Segal, Wein, & Cherney, 2000; and Wallace, 2001). However, most of these studies have had a primary focus on intervention during the treatment phase and palliative or end-of-life care, not during the time of *transition* from one to the other. Though a few studies have targeted assessment processes (Emanuel, 1995; Fitch, 2000; and Henderson, 2000), and suggested interventions (Davies & Oberle, 1990; Norton & Bowers, 2001; Reimer & Davies, 1991; Ronaldson & Devery, 2001), little seems to have been researched or written about the way in which expert nurses pick up on cues of patient readiness to talk about the meaning of the patient’s experience of transition. The need often occurs at critical junctures linked to news of disease progression and ensuing changes in treatment goals (Brennan, 2001; Chick & Meleis, 1986; Clark-Steffen, 1993; Doyle-Brown, 2000; Glaser & Strauss, 1965; Norton & Bowers, 2001; Ronaldson & Devery, 2001).

A growing body of literature addresses *physician-patient* communication related to the decision-making complexities which accompany advancing disease and failure of the treatment in either reversing or stabilizing the disease progression (e.g., Buckman, 1992; Carnes & Brownlee, 1996; Ptacek & Eberhardt, 1996; Weisman & Worden, 1985); yet, there is less about how *nurses* manage their interactions with patients and families. (A few exceptions include authors who address communication issues from the perspectives of physicians, nurses and other health care providers collectively and separately (e.g., Buckman, 1988; Buckman,1992; Degner & Beaton, 1987; Faulkner & Maguire, 1988, 1994; Sapir, Catane, Kaufman, Isacson, Segal, Wein, & Cherney, 2000). This is of importance as it is often the nurse who spends the most time with patients/families as they journey through this less-well-marked part of the road. Indeed, a significant study found that the third highest item of factors considered important at end of life by patients, families, physicians, and other care providers, was "having a nurse with whom one feels comfortable" (Steinhauser, Christakis, Clipp, McNeilly, McIntyre, and Tulskey, 2000, p.2479).

Bakker and Fitch (1998) assessed the top research priorities for members of the Canadian Association of Nurses in Oncology (CANO) and compared them with the top priorities of nurse researchers. Interestingly, communication was the number one priority for members (direct care providers, administrators and educators), but was in fifth rank for the researcher group. Concerns and tensions articulated in this study would appear to confirm that prioritization.

Donavan (1997) has commented on nurse practices and end-of-life decision-making by nurses in US hospitals, by asking why hospital nurses are not more involved in end-of-life discussions with patients (p.4). She describes three influencing factors: the nursing delivery system, nurse knowledge of and skill in palliative care, and system support. Her discussion concludes with the comment that the "only morally acceptable option for nurses is active involvement" (p.4). All eight values of the Canadian Code of Ethics (Canadian Nurses Association, 2002) underscore the comprehensive nature of ethical responsibilities for nursing practice.

Henderson (2000) and others (Donovan, 1997; Scanlon, 1997) challenge nurses to critically examine their opportunities, as well as personal and professional responsibilities, in participating in the improvement of end-of-life care. Henderson describes the issue as one of importance to public health, stressing that care at the end of life has been a hallmark of the nursing profession since the time Florence Nightingale described nursing caring behaviors for the dying. Glaser and Strauss (1965) observed that predicting the course of an individual's response—from denial to acceptance—to disclosure about the terminality of his prognosis, is often related to the kind of intimate knowledge the care provider has about the patient (p.125). Nurses in the outpatient cancer care setting frequently have opportunity to develop ongoing relationships with patients and families, and can thus prepare the way for their ability to cope.

In 1999, the Supportive Care of the Dying: A Coalition for Compassionate Care undertook an Organizational Assessment Project that involved eleven health care systems (McSkimming, Myrick, & Wasinger, 2000). Measurement tools were used to assess feedback from patients, family caregivers, and bereaved persons, with participants not necessarily being matched to each other by shared experience/circumstance. Overall patients reported that their experience in health care was a positive experience and that the physicians, nurses, and other care providers had made an "important difference to the experience" (p. 51). Though patient participants rated communication overall highly (greater than, or equal to 7 on a 1-10 analogue), an interpretation of some descriptive data indicated "that perhaps caregivers miss opportunities to talk openly about death and dying and to refer patients and their families to counselors or support groups" (p. 51). It was also expressed that if organizations "seek to bring about practice changes in end-of-life care, it is also important to determine the perspective of the health care providers" (p.

51). McSkimming, Myrick, and Wasinger also note that the largest group of professional health care respondents was *nurses* (43%), and that 59% of them reported having either referred patients to or suggested hospice services. This finding reinforces the need to explore further the nature of the nursing role as pivotal in facilitating patient transition to palliative care.

A generally-accepted understanding, reiterated by McSkimming, Myrick, and Wasinger (2000), is that many health care providers have a different perspective from that of most patients and family caregivers because these professionals are responding from an aggregate of experience, rather than from one—or at most, a few—deeply personal experience(s) (p. 52). This observation is not made to negate the poignant learning that can take place as a result of singular experience. Indeed, most health professionals who have personal experiences with the loss of their loved ones may readily acknowledge that such personal exposure profoundly affects their insight and responses to the experiences of others in ways that can add even broader and deeper dimensions to their accumulated experience in working with individuals outside their social family membership. Awareness of one's own vulnerability in the sharing of "mortal time" with patients and families is a part of the work that nurses must grapple with in transitional cancer care. Vachon, Kristjanson, and Higginson (1995) have indicated, in fact, that there is need for staff support programs and assessment of how such supports may impact on patient care, staff empathy, and improved patient/ family/ staff education.

Several points need to be emphasized here. Though the importance of patient perspectives and autonomy as the central focus of quality end-of-life care cannot be minimized or disrespected, as Bowman, Martin and Singer (2000) point out, it is also imperative to acknowledge another dimension of concern. Avoidance of parentalistic attitudes cannot absolve physicians and nurses from the professional duty to provide adequate informational support in order that patients can then make sound decisions. Nurses need to be especially cautious about this matter as there is a tendency for some nurses to lay the burden of information sharing at the feet of physicians claiming that is "their role," meaning "their role alone." Such belief about the professional role of nurses belies the values of their Code of Ethics and Standards of Care. Kristjanson (1994) demonstrated that need for informational support was ranked among the priorities of health care provider behaviours that are of importance to family care. If as caregivers we leave the total onus of decision making with the patient, we do them a disservice. Guadagnoli and Ward (1998) point out in a literature review of patient participation in decision making that patients by and large indicate their preference for *shared* decision-making processes. Degner and Beaton (1987) reveal similar findings in their broad study of life-and-death situations, and Degner and Sloan (1992) also support this preference for shared decision-making in their study with patients who had serious illnesses.

Kelner and Bourgeault (1993) researched the responses of health care professionals (nurses and physicians) to the increasing desire of patients to exert control over the circumstances of their dying. They suggest that professionals are required to concede some of their autonomy and power in order to enter into partnership with patients in the decision-making process, a position that may benefit professional care providers as a result of having access to patients' insights and experiences, and diffusion of the burden of responsibility (p.764). Patients may also benefit. Hofmann et al., (1997) concluded from the findings of their study designed to measure hospitalized patients' preferences and characteristics in relation to communication with physicians about end-of-life decisions, that unwanted intervention is often associated with a failure to discuss preferences about cardiopulmonary resuscitation and mechanical ventilation. Again, this was a study that was occurring within the hospital setting. Avoidance of situations of undesired intervention—situations in which patient wishes have neither been elicited nor potentially honoured—might possibly be addressed with discussion of the issues earlier in the illness trajectory so that shared decision-making can be actualized as a normative part of outpatient care. Sadly, barriers of race, younger age, and poor quality of life were also identified in the study by Hofmann et al. (1997) with patients' unmet wishes and need for entering into end-of-life discussion with physicians in the hospital setting. Such barriers are important to address if patients are to benefit from shared decision-making opportunities.

According to Weeks et al.(1998), adults with advanced lung cancer or colon cancer metastatic to the liver were significantly less accurate than their physicians in predicting survival, with patients tending to over-estimate survival. Why is this an issue? As Baumrucker notes in his editorial (1998), it matters because there was a concomitant tendency for these patients to choose "life-extending" care over "quality-of-life" care (i.e., palliative care). Furthermore, those individuals who chose "life-extending" interventions showed no statistically significant increase in survival and were 1.6 times more likely to experience readmission. One has to question *why* the choice for palliation was postponed or made seemingly inappropriately late.

Baumrucker suggests that there is need for shift to earlier discussion and integration of palliative care; and though he thinks that *science* should not have to tell us that, dialogue from the team of caregivers is key to appropriate decision-making. He concedes that the time is right for research to convince us of what seems to be obvious. What he ignores, however, is the complexity of the issue. It is not *just* that the skills of talking with patients about dying is rarely taught—though these skills certainly *do* need strengthening through educational approaches. Other barriers and complexities can be identified, too, and this next section will help to illuminate some of them.

Complexity

In Chapter 1, the quandary that faces nurses in cancer care about patient receptivity or readiness for transitional thinking was raised through sample "in the field" comments of experienced practitioners. Guadagnoli and Ward (1998) suggested after their literature review of patient participation in decision making that "interventions could vary depending on the 'readiness' of the patient" rather than an ad hoc application approach (p.337). Though they were looking at patient participation in decision making, there is an interrelatedness to the focus of this study.

It cannot be presumed that all individuals with physiological metastatic advancement of their cancer will be ready to acknowledge that they need to change their focus from seeking cure to one of "getting things in order," a phenomenon associated with palliative care. This presumption, however, seems to be the premise on which Norton and Bowers (2001) based their study. These researchers asked nurses and physicians how they worked toward shifting the treatment focus, or the overall understanding of the "big picture," of patients and families from "unrealistic" (i.e., curative) to “realistic” (i.e., palliative), the latter being associated with improved possibilities for a “good death.” Though the patient’s right to self-determination is noted, the authors point out the complexity of adhering to the principle in practice. The underlying truth to their claim is acknowledged; however, their premise is problematic in that their definitions of “realistic” and “unrealistic” are somewhat narrow and value-laden. Furthermore, their gestalt of the patient’s condition is described as being constructed on knowledge filtered through the lenses of care providers, with numerous life dimensions and values/beliefs not addressed (p.262). “Shifting the picture” was likened to getting patients/families “on the same page” as the care providers. One has to question if that is truly reflective of sensitive respect for patient autonomy. Granted, decisions are usually best made on the basis of sound information; but professional care providers need to be vigilant about their purview of influencing the decisions of patients solely from the perspective of the professionals’ views of what that information may entail. Nor can we presume that professional care givers are always in tune with the individual’s readiness to participate in such a change of care direction. As reinforced by Ronaldson and Devery (2001), the “complexities for all concerned in the process of referral to palliative care services cannot be underestimated” (p.1). Others agree (Ashby & Stofell, 1991; Jeffrey, 1995; Lowden, 1998).

There are for instance, complexities arising from medical uncertainties, health care organizational structures, and existential issues; and the situation is made even more complex by the interrelationships among these already multifaceted factors. Some of the more important elements have been discussed in the literature and are discussed further in the following section. Though the following factors are not purported to be fully comprehensive, discussion includes:

- quandaries surrounding prognostics
- appropriate timing of referrals to palliative care, balanced with the angst associated with facilitating, supporting patient transition and the inherent discomfort of that process
- the need for time to establish trust before entering mortal time with another
- clinical and organizational confusion in operationalizing the conceptual definition of palliative care
- issues of ineffective access processes and lack of public and professional awareness of these processes and opportunities
- limitations of placing communication solely within the patient-physician context
- inadequacy of communication
- ethical and moral considerations
- economic constraints
- other confounding contextual influences.

Quandaries about prognostics and timing of referrals to palliative care services

Jeffrey (1995) observes that "specialist palliative care nurses and hospice units emphasize the importance of early referral of patients if the highest standards of care are to be achieved" (p.123) but he does not state why he or those nurses have drawn that conclusion. He also indicates that the reason general practitioners do not refer to [palliative] specialists "until 'the end'" is because they are uncertain about the rate of progress of the disease (p.123). Though he himself is a general practitioner, this reasoning is not substantiated with research and may be reflective of erroneous assumptions and a too narrow view of other complexities involved in the decision making about referral. Lamont's and Christakis' (2001) study about prognostic disclosure to patients with cancer near the end of life, in fact, has reported that physicians would report a frank estimate of survival, even if patients with cancer requested the information, only 37% of the time, and the remaining times report no estimate, or a conscious overestimate/ underestimate. These authors purport that this pattern "may contribute to observed disparities between physicians' and patients' estimates of survival"(p.1096), such as was found in Week's (1998) study. Is such a finding in keeping with Jeffrey's reasoning, or is there more to the question? (A recent study of referral patterns in Wellington, New Zealand, reflects a desire for goals of earlier referral as their current rate of "near death" referrals was 20% (Massarotto, Carter, MacLeod, & Donaldson, 2000).) Howell, Fitch and Deane (2003a) reiterate the belief that earlier access to palliative care programs is "important to ensure that these women [with ovarian cancer] are receiving the highest quality of symptom control and the psychosocial counseling required in dealing with fears related to the future and preparation for advancing illness and death" (p.9).

Though the body of literature and numbers of services related to palliative care and hospice care continue to grow, there is still little articulation of knowing how to recognize patient, family and care provider readiness to enter into discussion about end-of-life concerns. In fact, while there is now more acknowledgment about the importance of these issues and the time needed to process them with patients/families (Emanuel, 1995; Jeffrey, 1995; Johnston & Abraham, 2000; Norlander & McSteen, 2000; Norton & Bowers, 2001; Norton & Tolerico, 2000), SUPPORT (1995), an extensive Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, confirmed the process is still often done poorly (Principal Investigators, p.1591-1598). Notwithstanding the complexity of the psychodynamics of the patient's coming to an awareness of his/her prognosis (Johnston & Abraham, 2000; Lamont & Christakis, 2001), the "knowing how" and "knowing when" of *timing*, as well as the "knowing who" and "knowing what" of *telling*, are critical to quality patient care.

It certainly challenges the clinician to reflect further as to reasons for clinical and moral dilemmas surrounding the issue of appropriate timing of referral. Lowden's study on introducing palliative care (1998) revealed that nurses' support for an earlier introduction of palliative care services was linked to an emphasis on emotional support. This was in contrast with the medical staff view of symptom management as a being the hallmark of palliative care. Both opinions are valuable, and need to be juxtaposed in such a way that patients benefit. Kristjanson et al. (2001) note comments from nurses that associate good death and timeliness of referrals (p.136).

The angst of entering into mortal time

Perhaps there *should* be reason to pause and grapple with issues of responding to the angst of decision making that impacts on the deeper existential concerns of individuals who are living with advancing disease. After all, *shoulds* and *oughts* are reflective of the health care professional as moral agent. Though the felt need of professional care providers to assist patients' transfer into care services focused on palliation may be well-intentioned, it none-the-less concurrently moves many patients into a state of transition—a state of shock, chaos, and uncertainty.

The experience of recurrence is often overwhelming and devastating (e.g., Gregory & Russell, 1999; Howell, Fitch & Deane, 2003b; Mayer, 1998; Weisman & Worden, 1985), associated at times with needed decision-making that occurs in the context of a perceived labyrinth of second, third, and even fourth-line treatments that are increasingly available. The word "palliative" as an adjective is introduced by some caregivers during this time to describe goals of radiation, chemotherapy, and supportive treatments. This change in their "cancer status" has been described by some individuals as "shocking," and as an "existential chill" (Fitch, 2000; Gregory & Russell, 1999; Howell, Fitch & Deane, 2003b; Mayer, 1998; Rogers, Karlsen & Addington-Hall, 2000). In their discourse on "existential plight in cancer," Weisman and Worden (1976-7) cite a poignant example of negation in response to being informed of a cancer diagnosis, in which one woman said "that she didn't know her diagnosis and she wasn't ready to know it!" (p.7). One need only attempt to imagine grappling with such news personally. Clinicians frequently indicate that it is hard enough to be the one to introduce the concept and explain the philosophy of palliative care and options available (Jeffrey, 1995; Johnston & Abraham, 2000; McQuellon & Cowan, 2000; Tulsky; 1998; Wakefield, 2000).

Fitch (2000) notes the challenge of addressing supportive care needs in a manner that recognizes the individuality of each patient-family situation, the complexity of the required supportive interventions, and the importance of partnership between health care providers and patients, partnerships that require trust and time to build (p.41-42). In their article entitled The kitchen table discussion: a creative way to discuss end-of-life issues, Norlander and McSteen (2000) echo these observations, pointing out the need for comprehensive assessment in advance health care planning, as well as the recognition such planning often takes place over several visits, rather than one lengthy one. Feedback from respondents in the study by Rogers, Karlsen & Addington-Hall (2000) indicated perception that "health professionals were immune to the devastating impact of a terminal prognosis," or that the prognosis was shared at an inappropriate or unwanted time (i.e., "they were unprepared for it," "[he] never wanted to be told he was going to die. It was on his hospital notes that he did not want to be told") (p.770). From the other side, there is some difficulty for care providers that arises out of concern for dashing the hopefulness of patients, and a recognition that transition of any kind can evoke uncertainty, disruption, even chaos (Bridges, 1980; Davies, 1995; Davies, Reimer & Martens, 1990; Mercer, Nichols & Doyle, 1988; Ptacek & Eberhardt, 1996; Ronaldson & Devery, 2001; Selder, 1989;Weisman & Worden, 1985).

Systemic confusion and inconsistencies

Many patients do not understand the actual meaning of the term "palliative;" they can only describe personal awareness that their mortality is involved somehow. Indeed, there is discrepancy of understanding and application even among the professionals who may introduce the concept to the patient, often influenced by such factors as eligibility for palliative care and hospice programs and services (Ronaldson & Devery, 2001; Payne, Sheldon, Jarrett, Large, Smith, Turner, & George, 2002). Payne and co-investigators (2002) reviewed the differences in understanding of specialist palliative care amongst service providers and commissioners in South London, and their findings confirm a lack of consensus about definitions of palliative care, ambivalence about referral procedures, and a lack of role clarity between specialist and generalist providers. In their description of an interprofessional program for palliative care education, MacDougall, Mathew, Broadhurst and Chamberlain (2001) identify that confusion over definitions of palliative care was an issue that needed to be addressed in the curriculum (p.24). Pickett, Cooley and Gordon (1998) note that "strides in cancer therapy have blurred the distinction between hope for a cure and the recognition of terminal illness"; and, that "blurring" contributes to the need for clinicians to enhance integration of palliative care principles of quality and meaning of life and death *earlier* in the care trajectory for patients receiving "active treatment" (p.86). Perhaps complexity, or blurring is further created through professional verbiage. Frequently the term "active treatment," as noted in the previous citation and frequently used in cancer care, is associated with interventions that have curative intent. Yet many treatment interventions clearly provided for palliation of suffering—not cure—such as radiation for metastatic bone lesions and spinal cord compression, or regular interactions with a spiritual care advisor, or multidisciplinary assessment and intervention for pain and other symptom management, are most certainly "active" too.

One fundamental challenge cited by Fitch (2000), is "to ensure that patients know about the services, and that there is easy accessibility for them at the time they require the assistance"(p.42). Inherent to that fundamental challenge of information provision and timely response, is the ability for key professionals to recognize the need, especially for patients who may not be assertive or able to articulate their own needs and concerns.

Fitch (2000) further reports on her work with Librach, identifying that the lack of palliative care integration into cancer care systems is of concern. Primary issues relate to lack of funding, lack of education about palliative care, late referrals, and slow progress in the integration of services so that there is a seamless continuum with equitable access (Fitch, 2000, p.44-45). These points are reinforced in the fourteen recommendations for quality of end-of-life care for all Canadians (Subcommittee to Update Of Life and Death, 2000) and in the Death in America initiatives. Emanuel (1995) advises a process of "structured deliberation," asking permission of patients to undertake discussion and ask relevant questions such as whom the patient would like to invite to the process, what cultural norms are important to the individual, and what they would like to ensure is brought to the process (S16-17). Unfortunately, as Rogers, Karlsen and Addington-Hall (2000) point out in their study on satisfaction/dissatisfaction with hospital care in the last year of life, some respondents indicated that they were never able to discuss [the patient's] condition or get adequate information, or blamed themselves for reluctance to ask questions (p.770-771). In citing Hume, Norlander and McSteen (2000) affirm that critical end-of life care discussions are too often "delayed until a patient is in crisis or too close to death to participate" (p.532). It is in just these sorts of circumstances that care providers then feel they have missed the boat, a disquieting feeling that leaves them in moral distress because they have in some way betrayed their values and their role as moral agents.

Communication in context: dying is not just a medical matter

Communication needs to be done more *effectively, consistently,* and in a *timely* manner in order to enhance the quality of life and relief of suffering of the *total* personhood of the individuals for whom we were providing care. Though most professionals agree these discussions need to take place, having them only happen within the context of the physician-patient relationship is inadequate (Davies & Oberle, 1990; Goodwin, Higginson, Edwards, Finlay, Cook, Hood, Douglas, & Normand, 2002; Henderson, 2000; Lowden, 1998; Norton & Bowers, 2001; Quill, 2000). Dying is not just a medical matter. Many would also acknowledge that end-of-life communication is neglected or left inadequately to a single discussion in practice. Some of this may be motivated by caregiver sensitivity about appropriate timing for broaching these difficult issues. Brolan's (1993) work on the nature of physician-patient-family communication over the course of chronic cancer care, noted the influence of time-pressures, economic constraints, heavy reliance on technical diagnostic cues in opposition to the use of perceptual and interactive cues of earlier eras. Comments from patients reflect their dissatisfaction with the timing and nature of these interactions (Johnston & Abraham, 2000; Ronaldson & Devery, 2001). In other circumstances, the issues may be avoided because of a sense of inadequacy or discomfort. For care providers who do manage to tread gently into the place of transition or "mortal time" with the patient, there is little guidance from research about how experts seem to know the "right" time to do this challenging work.

It is not surprising that one of the recommendations that came from the group of participants in the report of MacDougall et al. (2001) was a request for a session solely devoted to communication skills (p.28). In a review of the literature (67 articles) focused on the physician-patient relationship and the "breaking of bad news," Ptacek and

Eberhardt (1996) recommended enhancing the receiver's sense of control because that tactic is thought to be associated with adaptive coping efforts and positive outcomes, based on their discussion of the theoretical model of stress and coping. "Delivering the news at the patient's pace" was among the 13 most consistently identified recommendations, but the discussion of "timing" centered on issues of location, privacy, convenience, sufficient time without interruptions, and the physician's level of comfort for the transaction. Though these are laudable and valid considerations, there was no mention of the patient's personal "readiness" or comfort level to *receive* the news.

The prolific number of reports and articles generated as a result of SUPPORT (1995), (Berwick, 1995; Brody, 1995; Callahan, 1995; Emanuel, 1995; Hardwig, 1995; Henderson, 1996; Hiltunen et al, 1995; Hiltunen, Medich, Chase, Peterson, & Forrow, 1999; Marshall, 1995; Solomon, 1995; among others), as well as the debate about ethical and moral considerations related to physician-assisted suicide, confirm that the issues surrounding end of life remain fraught with a variety of opinions and clear need for ongoing research. The call for research with practical clinical application to enhance quality care for individuals who are living with progressing disease is compelling.

Bowman (2000) identifies numerous factors that contribute to the potential for conflict and discomfort in end-of-life decision making, including: family dynamics, varying beliefs, inconsistent prognostics, compromised care continuity, cultural and other demographic differences, geographical separation of family members and increasing life expectancy (S17). One could also add economic pressure on health care resources, and a perception that time allotted for serious discussion is not consistently valued. The SUPPORT principal investigators (1995) highlighted some other contextual factors leading to their study. These included: increasing medical knowledge and means to prolong life; a fear of prolonged and impersonal dying; an increasingly visible right-to-die movement, and public debate over the issue of physician-assisted suicide; statutes requiring informed consent, the Patient Self-Determination Act [PSDA]; and studies that demonstrate absent or inadequate physician communication (p.1591-1592). The need to better address preparation for end-of-life care has been reflected in the formation of related associations such as the Canadian Hospice Palliative Care Association, Education for Physicians in End-of-life Care, Project on Death in America, the increase in publications dedicated to the field, and in the remarkable growth of services in palliative care and hospice. Clark's work (2002) on following the development of hospice through the compilation of Cicely Saunder's correspondence highlights this growth in a creative way.

Intuition, common sense and anecdotal experience tell most people that individuals who have benefited from timely discussion of end-of-life issues from a holistic perspective experience improved quality of life, and for the most part are better prepared to live until they die. Research is beginning to better inform us about what factors are considered important at end of life by patients, families, physicians, nurses and other care providers (e.g., Kristjanson, McPhee, Pickstock, Wilson, Oldham, & Martin, 2001; Penson, 2000; Steinhauser, Christakis, Clipp, McNeilly, McIntyre & Tulsky, 2000). Furthermore, social families and professional caregivers of individuals who are dying also are able to process the experience of mortal time in a healthier manner because they are left with fewer regrets and can feel privileged to have been a part of something of deep personal value.

Moral distress, moral residue

Nurses report moral distress (Jameton, 1993; Kristjanson et al., 2001) and angst when they have felt that patients were unprepared for their demise. Moral distress has been described by Wilkinson and Jameton (in Jameton, 1993) as feelings of frustration, anger, and guilt that are the consequence of inaction, or conflict, or constraint, created by a sense of powerlessness to change the course of therapy in the context of a felt moral responsibility for the care being provided (p.543). Webster and Baylis (1999) add that "moral distress may also arise when one fails to pursue what one believes to be the right course of action (or fails to do so to one's satisfaction) for one or more of the following reasons: an error of judgment, some personal failing, or other circumstances truly beyond one's control"(p.3). Nurses observe that patients and/or their caregivers, are so caught up in a cycle of overtreatment, misplaced hope, and unfinished relational, spiritual, and financial business, that the patient's death and dying leaves nurses feeling a profundity of loss that contributes to an accumulative sense of moral distress.

Moral residue refers to remnants of the experience(s) of "compromised integrity that has involved the setting aside or violation of deeply held (and publicly professed) beliefs, values, and principles" (Webster & Baylis, 1999, p. 12)—remnants that may profoundly alter the concept of self and personal integrity for many years. Individuals in cancer care are perpetually dealing with the complex dimensions of professional and personal impact of observing others' cancer progression in spite of treatment, or the many dilemmas associated with treatment decision-making. Literature related to the need for professionals to be vigilant about the potential for disenfranchised grief (Marino, 1998;

Totka, 1996; Wakefield, 1999, 2000) would support this.

Jameton (1993) also raises the issue of bureaucratic and professional historical roles as important sources of confusion relevant to the essence of this study. “The division of labor between nurses and physicians also continues to be a source of moral distress. …roles are divided in a way that is inefficient, morally problematic, and ultimately burdensome to those who must play its parts” (p.549). Jameton’s injunction to emphasize care planning as collaborative, with less emphasis on dominance in decision making and more on shared responsibility and cooperation, is supported by citation of situations where such approaches have reduced the instances of reactive moral distress and outrage (p.549). Jameton’s (1993) review of the perspectives of individuals enmeshed in the influence of institutional and professional customs where there are dynamics of power positions, is reiterated in concept by a few of the articles published by the Hastings Center in a special supplement (1995) as invited responses to the report of SUPPORT (Annas, 1995; Berwick, 1995; Marshall, 1995; & Brody, 1995). It is noteworthy, especially since nursing participation was critical to the SUPPORT study intervention, that the Hastings Center supplement did not have a nursing contribution to the review (Henderson, 1996). Henderson (1996) and Curtain (1996) did, however, publish their views on the matter. (Interestingly, representation from the faith community to discuss spiritual care as a significant contribution to quality of life and the dying process was also absent in the Hastings Center special supplement.) An individual who dies peacefully does not do so solely because medical management has been effective. Power struggles among professionals must be acknowledged, processed and then reduced in order to maximize the collaborative strength of entering into mortal time with those who are in need. Norton and Bowers (2001) cite findings from their physician and nurse informants who underscored the need for collaboration because of the devastating and stressful results for the patient and family if care providers are either inconsistent, or in conflict as care options are discussed. Payne et al., (2002) also highlighted the challenges of hierarchical function as less than ideal for working relationships as an outcome of their study of palliative service provision in London (p.399).

There is no doubt that effective health care interventions of a *team* of individuals with a variety of expertise may contribute valued support to the dying individual and his or her social family. The influencing factors on discussed in this section are necessary to consider when threshing out the complexities of facilitating healthy patient transitions to palliative care, while minimizing moral distress of professional caregivers.

Theoretical Framework: Explanatory Models

Kleinman's (1992) theory of explanatory models (EMs) is used as the primary theoretical framework to provide a sensitizing perspective while exploring the phenomenon of interest. His theory contends that people use explanations for individual behaviors based on the intersubjective reality of both their single reality and their social reality, a "flow of interconnected attention, feeling, and social cognition. The categories that we use to make common sense of things, the language structures that we master and manipulate, the day-to-day and extraordinary relationships and networks in which we engage, the social institutions in which we participate—all connect our inner world to social forms" (p.129). In other words, EMs are culturally constituted explanations for illness and its treatment (Kleinman, 1980) and can be used to guide culturally sensitized assessments. Comments within this paper reflect just such approaches (Selder, 1989; Emanuel,1995).

One way to understand the flow of interpersonal relationships is "to elicit the explanatory models of key informants:...patient, family, friends and health care providers" (p.130). Kleinman refers to nursing as a "human practice" (p.128), and the felt experience of human illness as the contextual "field" in which nurses function. In pointing out the usefulness of EMs in developing either the meaning of illnesses or in studying the therapeutic (care) experiences, Kleinman cautions against superficial descriptions, which can be stereotypical, as well as against using just the single channel of verbal communication (p.131). This is one reason why researcher observations about the contextual channels of sight, sound, touch, smell, perceptions, and non-verbal communication factors were recorded in this project. It is believed that these sources of observational data provide important learning in conjunction with the person-centered interviews and focus groups. Kleinman further encourages appreciation of the local context's political, economic, institutional, relational and cultural patterns in their application to health care issues (p.133). Certainly attention has been given to these factors in this chapter, especially to the manner in which context influences the complexity and nature of communication and the nursing role in transitional-palliative cancer care, and the methodology and findings chapter further underscore contextual influences.

A review of the literature related to clinical use of EMs as a sensitizing concept demonstrates further that understanding explanatory models of either illness or care can serve as a basis for negotiating therapeutic interventions (e.g., Ahlqvist & Wirfalt, 2000;

Alcozer, 2000; Facione & Katapodi, 2000; Mahoney & Engebretson, 2000; Reifsnider, Allan & Percy, 2000; Russell, Geraci, Hooper, Shull & Gregory, 1998; Sarvimaki & Stenbock-Hult, 2000; Sayre, 2000). In fact, understanding the *differences* between EMs of lay persons and their health professionals may diminish potential communication issues and lead to improved knowledge, understanding and health outcomes (Ahlqvist & Wirfalt, 2000; Russell, Geraci, Hooper, Shull & Gregory, 1998). This is the underlying goal of this research study. Other studies with similar, yet different perspectives on the nursing role in transitional and palliative cancer care will now be reviewed, before discussing methodology in depth in the next chapter.

Related studies: comparisons and contrasts

All four research studies highlighted in *Table 1*. Related studies involving nurses in the transition to palliative care focus in some way on nurses' perspectives on their role and /or issues related to end-of-life decision-making and transition from curative care to palliative care.

Table 1. Related studies involving nurses in the transition to palliative care

	Davies & Oberle (1990)	**Kelner & Bourgeault (1993)**	**Norton & Bowers (2001)**	**Ronaldson & Devery (2001)**
Central question	What are the dimensions of the supportive role of the nurse in palliative care?	What are the responses of health care professionals to questions of patient control over the dying process?	How do health care providers work at the end of patients' lives toward changing the treatment decisions of patients and families from those decisions that are 'unrealistic' (i.e., curative) to 'realistic' (i.e., palliative)	What is the experience of transition to palliative care from the perspective of patients and acute care and palliative care nurses?
Sample	• Purposive • one expert supportive care nurse	• Purposive • 20 nurses, 20 physicians; 5 each per four clinical settings	• Purposive (letter of invitation to participate) • 10 nurses, 5 physicians, 5 family members* • (* report of this data not included in this article); • theoretical sampling built in to design of interviews	• 11 inpatients newly transferred to palliative care; • 5 nurses with "extensive experience" in dealing directly with inpatients undergoing transition to palliative care • 2 focus groups of 6 nurses each
Setting	Pain and symptom control clinic at a cancer treatment centre in a Canadian prairie province	Inpatient tertiary hospital care in a major Canadian city in Ontario, used four clinical specialties: oncology, gerontology, ICU & family practice	mid-size Mid-western city, USA; Intensive care, oncology, family practice and home health	Large inner metropolitan health care campus (acute care teaching hospital and palliative care service) in Australia
Methodology	• Descriptive, qualitative design. • In-depth retrospective descriptions of care for patients and families elicited from one nurse about 10 exemplary palliative care situations from the previous five years of her caseload • Recall was facilitated by the use of the health care record to provide cues	• Individual semi-structured interviews with two groups of professionals	• Grounded theory based on theory of reconciling decisions near end of life; first four open-ended interviews, then more focused on evolving categories	• Interpretive research of a qualitative descriptive design; • Individual semi-structured interviews; 2 focus groups.

	Davies & Oberle (1990)	**Kelner & Bourgeault (1993)**	**Norton & Bowers (2001)**	**Ronaldson & Devery (2001)**
Analysis & rigor	• Constant comparative analysis • theoretical saturation • phenomenon recognition by 4 other nurses	• Content analysis & concept saturation • No mention of how participants validated findings	• Constant comparative analysis • Member checking ongoing, with 3 of 15 interviewees having second interviews	• Qualitative content analysis; member checking not identified as part of process; but "results given to relevant expert nurses who were external to the study & who recognized the results from their own experiences"
Findings	Six dimensions of the supportive nurse role in palliative care: 1. Valuing: 1.1. Global 1.2. Particular 2. Connecting: 3. Empowering 3.1. Facilitating 3.2. Encouraging 3.3. Defusing 3.4. Mending 3.5. Giving Information 4. Doing for 4.1. taking charge 4.2. team playing 5. Finding meaning 5.1. focusing on living 5.2. acknowledging death 6. Preserving own integrity 6.1. looking inward 6.2. valuing self 6.3. acknowledging own reaction Nurse as professional cannot be separated from the nurse as a person. Further research in the role of the nurse in supportive care needed.	Responses varied; influenced by specialty, patient circumstances, personal moral scruples, legal concerns, type of intervention requested by patient; Core themes: 1. patient control represents a challenge to clinical judgment 2. care providers' perception of role as healer/supporter 3. physicians feel a challenge to their professional autonomy and power 4. concerns about impact on personal ethics and potential for legal liability Nurses more comfortable with team decision making, shared responsibility than physicians. Those with power must agree to share it with those they treat.	• Shifting patients' (and families') decisions from curative to palliative was usually accomplished by changing their understanding of the "big picture" (what was really going on) to one that was consistent with the providers' understanding. Strategies in the areas of 1. Laying the groundwork (teaching, planting seeds); 2. shifting the picture (working together/ consensus among providers, family meetings, creating new expectations, changing scope of choices, value of options, and indicators); and 3. accepting a new picture (involving other supports, redirecting hope, repeating information)	• Core themes: 1. pace and timing of referral and transition (i.e. of location to palliative care service) 2. fear and misunderstanding of palliative care 3. accepting palliative care 4. information about palliative care 5. education 6. peer support and supervision • Recommendations: 1. Preparation needed for the transition process to alleviate fear and anxiety. 2. Improved access to information, on an individual basis, and at a time when patients are most ready for it. 3. Palliative care education should be routinely utilized, with focus on communication around disclosure 4. Support nurses working in isolation.

Davies and Oberle (1990) set out to describe the clinical component of the role of an expert supportive care nurse who, through in-depth interviewing, was asked to recall memorable situations in caring for ten individuals and their families. The patients and families were mostly receiving palliative care through the services of an outpatient care setting—a pain and symptom control clinic—as well as home care in the previous five years of the nurse's practice. Kelnor and Bourgeault (1993) focused on the *locus of control* over decision making about the dying process, and how that affects professionals'(i.e., physicians and nurses) perceptions; while Norton and Bowers (2001) looked at determining how care providers *shift* the decision about treatment goals, based on the presumption that this is what *should* be done out of the motive to facilitate a "good" death.

The thesis project at hand differed in that it explored nursing observations about how they perceived patients' *readiness* for thinking about palliation and all that may mean for the individuals and their families, asking nurse participants about their role in that transition of care goals. This difference in approach is based on the premise that patients may *not* make a shift in their thinking, unless they are ready to do so. This need is borne out in the findings of Ronaldson and Devery (2001). (Norton and Bowers have yet to report on the findings from family members in their study.) The most notable difference in intent in these studies is that two (Norton & Bowers, 2001; Ronaldson & Devery, 2001) have involved either the patient or their family members, requesting their retrospective views. Three of the studies in some way touched on outpatient services, while one was exclusively related to transition within a hospital setting, with the transition referring to a timeframe that was closer to end of life for the patients. This current study seeks to get at information that will help explore and describe if and how nurse care providers discern patients' *readiness* for that interaction, presumably at a time that is early enough in the illness trajectory to have optimal autonomy for the ILWPC, and what contextual factors influence nurses' processes of discernment. Following that acquisition of knowledge, research will then need to be done with persons living with an advancing illness to assess whether the nurses' reading of the individual's readiness to enter mortal time discussion, through application of the findings in clinical practice, is/was accurate.

All studies have used qualitative approaches which speaks to the complex nature of the underlying phenomena.

Conclusion

From a review of the literature it is evident that there are numerous challenges to health care providers as they seek to determine just how and when to introduce the idea of palliative care to ILWPC without compromising their hopefulness. There seems to be consensus that timeliness and sensitivity in communication is needed because many studies have indicated the challenges arising from the shock and angst that is experienced by patients and their social families upon receiving and then living with news of disease recurrence. The transition into mortal time is fraught with uncertainty and necessary decisions.

Numerous areas related to end-of-life issues and health care for ILWPC are still requiring further research. The whole concept of transition from acute care to palliation is under-researched, but has in the last decade or so become increasingly important as cancer itself takes on greater chronicity as an illness. Since more adjuvant therapies are now available and as symptoms of illness progression can be muted with some therapies, longevity of the patient has increased. It has become concomitantly more challenging to determine timing of discussion of end-of-life issues; but the alternatives of leaving such important matters until persons are too ill to be participants in their care planning is a less than desirable outcome to consider.

Thus, this chapter has reviewed relevant areas that need to be considered as background to this project which has attempted to illuminate at least some of the nursing role in transitional cancer care. One aspect of care that is somewhat nebulous and poorly defined in the literature—admittedly in the context of a complexity of related issues—is that of discerning the patient's readiness to receive information at a time that will cause the least amount of harm to hopefulness and that will assist the ILWPC in getting the necessary support to do the work of transition. It has been felt that expert nurses may be able to contribute to that much needed body of knowledge because they are often in a position of recognizing readiness behaviours of persons for whom they are caring, especially in relationships over time as treatment and follow-up in cancer care is being provided. Seeking better understanding of these thinner areas of knowledge in mortal time care was the purpose of this study.

The next chapter highlights the methodological considerations in researching the problem of exploring and describing the nursing role in transitional cancer care with particular emphasis on timing discernment, barriers and enhancers to effective outcomes of care based on the insights of expert nurses who do this interrelational work with ILWPC on a regular basis.

CHAPTER THREE

THE RESEARCH DESIGN

Introduction

Chapter Three identifies the rationale for the exploratory descriptive qualitative approach used in this study. It fits the nature of the question and the need to explore aspects of the nursing role in the complexities of transitional cancer care. An overview of the research plan is provided, including a description of person-centered interviewing and focus groups as methods for data collection, strengths and weaknesses inherent to the design and the means taken to demonstrate its inherent trustworthiness. Explication of the design elements include description of the purposive selection process for respondent-informant participants and their attributes, along with data collection, management, and analysis. Study limitations and ethical considerations that influenced the design in respect for the nurse participants and appropriate processes conclude the chapter.

Selected methodology and rationale: strengths, weaknesses, and trustworthiness

Much debate exists in the literature about the relevance and rigor of qualitative methods of inquiry, with a proliferation of textbooks and articles centered on the contrast, comparison, and complementary nature of quantitative and qualitative approaches. Authors identify issues such as: scientific adequacy (Sandelowski, 1986; Streubert & Carpenter, 1999); whether or not the same quality criteria can or should be applied to both qualitative and quantitative methods (Pope & Mays, 1999); the meaning of truth in the context of the inquiry process (Lincoln & Guba, 1985); and, statistical representation versus the perceived "stigma of the small n" or judgmental sampling (Polit & Hungler, 1995; Pope & Mays, 1999).

As outlined in Chapters One and Two of this study, transitional cancer care is complex. There is not yet consensus about defining transitional care and just when palliative care begins. Less has been studied about cues or behaviours of patient readiness for discussion of palliative care and end-of-life issues. However, these cues impact the attendant everyday, taken-for-granted behaviors of nurse-patient interactions with ILWPC during such times. As described in Chapters One and Two, "mortal time" (McQuellon & Cowan, 2000) interactions are complex human behaviours related to decision making in a social context of personal crisis, transition, deeply felt values, and meanings. Several influences add to that complexity, including the context of outpatient care, team members who function within socially-stratified organizational cultures (Carline, Curtis, Wenrich, Shannon, Ambrozy, & Ramsey, 2003; Emanuel, 1995; Jameton, 1993; May, 1993, 1995) and larger interacting social systems of health care delivery (Mee & Robinson, 2003; Pope and Mays, 1999; Radwin & Alster, 1999). As health care relationships deal with subjective human behavior requiring complex interpretive methods, discovery of comprehensive terms to describe the nature of interactions which otherwise remain ambiguous and fraught with misunderstanding or assumptions has been found helpful.

Selection of a qualitative research design for this study was based then upon the subjective, investigative, complex nature of the central question. Qualitative research methods were expected to be sounder than quantitative methods. According to Pope and

Mays (1999), qualitative research can be used quite independently of quantitative inquiry in order to "uncover social processes...which are not amenable to quantitative research" (p.6). These authors note further that "qualitative research explores people's subjective understandings of their everyday lives" (p.6), and helps to "make sense of the world," that is the "social world we live in" (p.7). Qualitative methodology is considered appropriate when little is known about a phenomenon (Polit & Hungler, 1996, p.18), or because of perceived biases or omissions concerning what is known. Furthermore, qualitative methodology permits the researcher to deconstruct what may have come to be commonplace so that core meanings can be revealed (Sandelowski, Davis & Harris, 1989). The theoretical framework of Kleinman's explanatory model as described in Chapter Two fits well with this methodological understanding. Thus an exploratory, descriptive qualitative approach, using both person-centered interviewing and focus group interviewing, was chosen to elicit detailed descriptions of the role of nurses in their work with ILWPC (Pope & Mays, 1999; Sandelowski, Davis & Harris, 1989; Strauss & Corbin, 1990).

Discussion of the chosen qualitative approaches

An in-depth description of the multiple methods (i.e., person-centered and focus group interviews, enhanced with researcher observations and reflections) chosen to elicit data follows, with discussion of their inherent strengths and weaknesses.

Person-centered interviewing

Person-centered interviewing, as described by Levy and Hollan (1998), engages the interviewee as "informant," a "knowledgeable person who can tell the interviewer about culture and behavior in a particular locale" (p.335). The method "engages the interviewee as a "respondent," as an object of systematic study and observation in him-or herself" (p.335). The authors explain that behaviors, actions, and responses of the interviewee to probes and questions, within the context of the interview, are also observed. Thus, the distinctive quality of person-centered interviewing is the balanced combination of informant-respondent roles that participants play (p.336). Information provided by the interviewee as an "expert witness" to general cultural processes, such as a nurse describing palliative care referral processes within an institution or health region's organization, may reflect the *informant* mode. Conversely, exploration of what happens for the nurse in her experience of approaching a patient, or responding to a patient's "invitation" to discuss care options in the light of news of advancing cancer, may provide *respondent* information. Levy and Hollan (1998) note that for social and psychological interpretations, the two types of information complement each other as the interview integrates informant-respondent modes in an oscillating, descriptive flow (p. 336).

Movement back and forth between the modes further "illuminates the spaces, conflicts, coherences and transformations" between the interviewee and aspects of perception and understanding of personal external context (p.336). Data generated by person-centered interviewing may then illuminate new phenomena which must be interpreted noting both content and form of the responses (p.337). Implicit to the method is interviewer understanding of the standard language so that the interviewer can recognize the significance of what is being communicated, and avoid the potential for distortion of people's private realms of experience (p.337-338). in this study, for example, the interviewer explored participant perceptions of terms such as "transition" in cancer care, "palliative care," and their understanding of patient "readiness" behaviours. Russell (1994) concurs with Levy and Hollan in their injunction for the need to clarify language, noting further that not only does such fluency improve rapport, but that rapport is conducive to getting at the truth of the matter because informants are less likely to distort it (p.145). He also advises that naïveté may not be effective if the perceived competence of the researcher is of relevance to the study participants (p.150). According to some, then, the interviewer must understand the culture (Levy & Hollan, 1998; Russell, 1994).

The downside to this view has also been argued (Pope & Mays, 1999; Russell, 1994). Indeed, Pinch (1993) has suggested that if researchers are "strangers" to the phenomenon under study, they may learn more about it. In addressing this side of the debate, Russell (1994) points out that it is harder to recognize cultural patterns and not take things for granted if you are studying your own culture (p.154). He suggests preparing oneself for studying one's own culture by reading the experiences of others who have done so (p.154). This was done as I explored perceptions with others prior to, during, and following the research process. The privilege of participation in the joint Summer Research Institute, sponsored by the Manitoba Nursing Research Institute and the Mayo Clinic in Rochester, Minnesota, was especially helpful in discerning how I would manage these aspects of the research process and in contributing to the refinement and awareness of personal preconceptions of issues related to transitions and end-of-life care. Finding a colleague for the purpose of debriefing regularly so that one can better transcend biases and maintain analytic abilities as one switches back and forth between the insider view and analyst's view is recommended (p.153). With this caution in mind, it was appropriate to have counter-balance and researcher awareness of personal biases, perceptions and assumptions, in addition to vigilance about being directive with informant responses, and controlling the expression of personal biases.

These considerations were especially pertinent for this study as the interviewer is a nurse familiar with the experience of the nursing role in facilitating transition of patients from curative to palliative care. In dealing with the participant cancer care nurses, I believe there *was* some enhancement to the process because of my perceived competence and understanding of the challenges of transitional cancer care; but bias potential was balanced with some naïveté of "how things are done *here*" because my work is located in a different kind of setting (i.e., a community hospital outpatient cancer clinic, rather than the tertiary care outpatient cancer care setting where a broader range of care interventions, such as bone marrow transplants, are provided). Awareness of potential for bias because of my role in cancer care contributed further to the decision to make reflexive notes and observations taken after each interview, and to share progress and these reflections with my advisor as the interviews and data analysis progressed. Observations and discussion with the transcriptionist further contributed to this balancing process in unexpected and helpful ways. She provided valued insights of someone from "outside the field"; yet she was an "insider" to the powerful stories of the participants, and needed time herself to debrief and discuss her personal feelings as a result of her exposure to their influence on her thoughts and emotions.

Strategies were integrated into the interview process to enhance openness, respectfulness for the views of the participant, and trust. The semi-structured nature of the interview schedule assisted in both providing some focus, while still allowing respondent-informant freedom to describe personal experiences and views more fully in response to the open-ended questions. Clarification of the interviewees' meanings by using questions such as "What do you mean by that?" or "What did you think about that?", or "Tell me more about that part of the experience for you," helped to diminish use of personal assumptions or interpretations on the part of the researcher. By employing the conceptual framework of explanatory models, the researcher was made aware of the need to use sensitivity and flexibility in trying to explore language, concepts, worldviews and meanings that helped to uncover ideas that were not anticipated. In summary then, in order to elicit fully the data it was vital that respondent-informant meanings were probed further and then validated to avoid relying on personal assumptions as the interviewer, a reliance that Pope and Mays (1999) caution against (p.13).

Concurrent analysis is also recommended by Levy and Hollan (1998), in order to pay attention to ways in which the interviewer needs to be aware of linguistic and interviewing errors which can be corrected in ensuing interviews (p.353). Personal notations in the left–hand column of early interview transcripts particularly, discussions with my thesis committee chairperson, and feed-back elicited by the interviewer from the focus group facilitator after the first interview were approaches used to assist in self-analysis and awareness of interviewing errors or areas for improvement. Observational notes about significant behaviors (such as visual aspects and body language not captured on audio-tape), events, contextual factors, notable shifts in the internal responses of the interviewer, or insights, were noted within hours after each interview and reviewed before ensuing interviews. Streubert and Carpenter (1999) also recommend that the keeping of a reflexive diary as part of the observational aspect of the methodology is an excellent way to explicate ideas, thoughts and opinions of the researcher so that influence on the data analysis is better revealed (p.21). These recommendations were incorporated into the methodology. Some of my reflections are included in the discussion of Chapter Five.

Focus Groups

The use of focus groups was selected as the second method of data collection. As previously noted, both the nature of the question and the paucity of literature to guide nursing practice, education, or research in transitional cancer care in determining cues of patient readiness, suggested the appropriateness of using focus groups as a qualitative approach that would help in data triangulation.

Though not all focus group processes can be considered research, focus groups may be selected as a qualitative research approach, and have been used extensively in market, social science, and health care research (Beyea & Nicholl, 2000a; Pope & Mays, 1999). A focus group is a forum that brings together a small group of people—recommendations in the sources reviewed varied from 4-8, 6-10 or even up to 15 participants—who meet for one to two hours in order for the research team to solicit participant opinions and beliefs on a given topic (Beyea & Nicholl, 2000b; Morgan & Krueger,1998; Pope & Mays, 1999; Streubert & Carpenter, 1999; Webb & Kevern, 2001). The facilitator or interviewer leading the discussion often uses a semi-structured interview guide to assist in eliciting information, an approach used in this study.

According to Morgan and Krueger (1998), "focus groups are fundamentally a way of listening to people and learning from them" (p.9), "a powerful means of exposing [the researchers] to the reality of those they need to understand" (p.57). Several authors also indicate the advantages for using focus groups in collecting sensitive data (Morgan & Kreuger, 1998; Pope & Mays, 1999; Streubert & Carpenter, 1999). Since this study involved discussion of issues that are inextricably linked with professional, moral, and existential dimensions of nursing, it was felt to be an advantageous approach of discovery.

The use of focus groups as a method of inquiry has numerous other advantages. The process of sharing and comparing different ideas and reflections among cancer care nurses provided a brain storming effect that produced useful insights and articulation of knowledge. Their use of personal clinical narratives provided rich data, reinforcing the observation of Morgan and Kreuger (1998) noted in the previous paragraph that focus groups can be "a powerful means" of sharing information about the issues in question. A great deal of information was gleaned quickly, while contributing to data triangulation (comprehensiveness) and credibility of the information.

There were hoped-for benefits for the participants, too. Nurses are not frequently given opportunity to "debrief," or share their thoughts and reflections about the intense nature of working in the cancer care context—especially given current workload intensity—as they work to facilitate care for increasing numbers of individuals with progressing cancer. Also, it was speculated at the outset of the research process that nurses in the group might learn from each other as they shared from their experiences. These speculated benefits of participation *were* articulated by the informant-respondent nurses and are discussed further in Chapter Five.

Given that there might be varied insights from nurses of differing levels of expertise, it had been hoped two homogenous focus groups could be used for information gathering, and then comparison and contrast of the data analyzed. The first focus group was to be comprised of "non-expert" nurses, and the second comprised of "experts." The "non-expert" group, described by Benner (1982) as, "advanced beginner," "competent," and "proficient" nurses (see Appendix F), was to be comprised of individuals who had identified voluntarily that they would like to gain more comfort and expertise in facilitating patient transitional care as the need for palliation presents. Though the numbers of voluntary respondents was limited, attempts to have informant-respondents who were trustworthy, observant, reflective, and articulate—qualities recommended by Russell (1994, p.168)—were not sacrificed in the process of arranging the group interviews. Three nurses only volunteered for the first group, and one volunteer had child care needs that pre-empted her attendance just prior to the interview. Possible reasons for the outcomes and potential benefits and limitations of the first focus group interview are discussed in Chapter Five.

Work with this group was held after the individual person-centered interviews, and prior to the second focus group of expert nurses. Focus Group 1 convened before the "expert" group because it was felt that competent or proficient cancer care nurses who were either perceiving themselves to be less "expert" than personally desired, or who may not have been designated by their peers as "expert," may prompt discussion and questioning that would then be explored with Focus Group 2, a group of voluntary nurses with expertise perceived to be exemplary. Interaction within Focus Group 2 would then be based on reflection and discussion of the data collected to that point so that the expert nurses group could further hone articulation of the phenomenon being explored. It had also been thought that nurses with less experience, less intuitive practice, or less comfort in dealing with mortal time might be encouraged in Focus Group 1 to reflect on dynamics that create barriers to their personal and professional development—factors that administrators, educators, and peers may need to heed in order to facilitate optimal patient care outcomes. Providing data about perceived barriers and other issues identified by both the individual peer-nominated "experts" and the voluntary participants of Focus Group 1 contributed to the direction of questioning for Focus Group 2, an interview with voluntary expert and experienced nurses, thereby strengthening the focus of inquiry and creating the potential to examine enhanced patient care outcomes.

Analysis of focus group data must also acknowledge that group format can help with understanding diversity and a variety of experiences while maximizing similarities (Pope and Mays, 1999). This benefit of group dynamics was expected as an enhancement to the methodology because individual interviews could not be expected to capture the same data that might come from the discussion of differing perspectives *among* nurses. While allowing for some diversity within otherwise homogenous groups, however, care was taken in group composition, avoiding the influence that hierarchy could have on the data, an injunction noted by review of Pope and Mays (1999, p.24). Indeed, awareness of this potential pitfall was the primary reason that the two focus groups were *not* collapsed into one when the researcher realized participant numbers were less than hoped for in the initial planning and methodological design.

Potential disadvantages of research using focus groups that have been identified in the literature (Beyea & Nicholl, 2000a, 2000b, 2000c; Morgan & Krueger,1998; Pope & Mays, 1999; Streubert & Carpenter, 1999; Webb & Kevern, 2001) often relate to a lack of effective moderation of group process (e.g., monopolization, hesitation of quieter participants, fear of attendance in a group setting precluding some participation, dominating opinions allowed to prevail ("group think"), biases of leader that get imposed on the group). Thus, interviewer skills in group process and in eliciting responses for purpose of the research focus, are paramount. Vigilance in ensuring the interviewer's skills at limiting direction while encouraging diversity of views and opinions, demonstrating sensitivity to potentially emotional responses, and knowing if, when, and how to probe appropriately, generally contributed to the success of the project. Limitations regarding Focus Group 1, however, are acknowledged and discussed in Chapter Five. Though I have had much experience in group process and as a group facilitator, my novice level of facilitation as a researcher was compensated by inviting an experienced focus group facilitator to be present for the group interview. As Streubert and Carpenter (1999) point out, an effective group leader can overcome the tendency to group think, and if accomplished, the advantages of focus groups as a data collection strategy can outweigh any disadvantages (p.24).

Questions from the original semi-structured interview guide, modified by the process of ongoing analysis and integration of data from the individual interviews of the peer-nominated expert nurses, provided a framework for both of the focus group interviews. Though an introductory video clip or two from a documentary of individuals with advanced cancer (How can we love you? (Sky, 2000), Wit (2001)), an approach noted in the literature (Morgan & Kreuger, 1998; Pope & Mays, 1999) was planned to start the discussion in the focus groups, they were not used according to the preferences and time-constraints of the participants. The participants indicated they had been doing some reflection on the topic in anticipation of the experience and felt positively about being able to share the time with their peers. Initial focus was thus simply accomplished by providing a draft of the transition model of the experience of ILWPC (Appendix B) as a visual tool to stimulate thinking about the nature of nursing interactions with patients during this part of the illness trajectory.

Observations and reflections

Throughout data collection, documentation was kept of observed personal feelings, perceptions, nuances, thoughts, sights, sounds, smells, and any other environmental or tacit cultural contextual factors that might have influenced the research interviews. Notation about the researcher role, how processes for gaining access were evaluated, and descriptive observations about what went on with each interview, were transcribed into a notebook as soon after the interview as possible to maintain as much integrity of the data and the research process as was feasible. Such observations influenced the need to develop further areas of questioning that had not been anticipated, and thus contributed to the richness and density of the data. For example, one of the earlier interviewees had described the phenomenon of transition as "gentle," a descriptor that would previously not have been associated in the researcher's mind with transitional behaviour. This idea then was explored further, and indeed alerted the researcher to pay heed to further such descriptors in following interviews. It was also a seed thought used for exploration and discussion in the focus group interviews.

The importance of descriptive field notes is underscored by Pope and Mays (1999) and Streubert and Carpenter (1999), and fits well with the conceptual framework of explanatory models (Klienman, 1992) and the method of person-centered interviewing

(Levy & Hollan, 1998), since both emphasize the need to consider contextual influences. Larger issues such as what was going on in the context of the institution, the profession or more global social and political circumstances, were also noted. Some examples follow. The impact of a possible nursing work stoppage (or other working conditions) were thought to potentially impact the explanatory model that each nurse would have about the quality of nurse-patient interactions in caring for ILWPC. Indeed, these observations were made by a number of the participants when arrangements were being made for the interviews, and even by some nominees who chose *not* to accept the invitation to participate. Personal reflections and questions were clearly diarized by me as a part of the collecting of observational data. The possible impact of a number of world events such as the events of September 11, 2001 as well as concurrent local nursing negotiations to renew the nursing contractual agreement are discussed further in Chapter Five.

Observational data analysis also focused on whether or not a topic came up in both groups, whether some participants were more interested than others, and for people who were interested, just how important certain topics were. Body language, plus other contextual factors such as light, sound, environmental comfort, weather conditions and anything else that is noteworthy, (including what may not have been said, or what topics got "derailed" and how that occurred), and nuances related to power dynamics within the group, were recorded and reflected upon. Technical difficulties with the recording equipment which had been pre-tested were not anticipated, but occurred. The effects of these challenges on me and possibly the study data are also further discussed in Chapter Five.

The groups worked with the facilitator to establish boundaries for diminishing stress (e.g., completion time, respect for the equanimity and confidentiality of contributions of all members, stoppage sign if individual(s) needed a break, the purpose of recording both by audio-tape as well as the facilitator note-taking), thereby enhancing both understanding for the need for trust and confidentiality, and in acknowledging the sensitivity of the subject matter. Review of other ethical considerations and respectful group process, along with the final completion of the consent process and papers which had been pre-distributed to the participants several weeks before the group meeting, were integrated into the introductions, throughout the group interviews, and at their conclusion.

Issues of Rigor

The need to pay attention to aspects of trustworthiness as integral to the worthiness of qualitative research has been described by numerous authors (Ingleton & Seymour, 2001; Lincoln & Guba, 1985; Marshall & Rossman, 1989; Morse & Field, 1995; Pope & Mays, 1999; Polit & Hungler, 1996; Sandelowski, 1986; Streubert & Carpenter, 1995, 1999). Approaches to enhance rigor or the trustworthiness of the research were used.

Based largely on the work of Lincoln and Guba (1985), and reiterated by the authors cited in the opening paragraph of this section, four criteria are generally used to evaluate trustworthiness:

1. *truth value* or *credibility* represents confidence in the truth of the data because those that have participated recognize the findings to be representative of their experience

2. *dependability,* which is met through securing credibility of the findings; thus is not plausible *without* credibility
3. *transferability*, *fittingness* or *applicability* refers to the probability that the study's findings have meaning to others in similar situations or have potential usefulness for other settings
4. *Confirmability*, or auditability, refers to the ability to illustrate the evidence and thought processes which led to the conclusions.

Credibility in this study was enhanced by meticulous record-keeping of the interviews, observations, a reflexive journal, and detailed documentation of contextual nuances in the environment. Timeliness of transcription and correction of any discrepancies between the audio tapes and the transcribed interviews, with multiple readings of the work as analysis proceeded were other methods used to ensure accuracy of the truthful representation of the participants' contributions. Use of the findings from the individual face-to-face interviews with the focus groups, along with the fact that in each focus group there was at least one nurse participant who had been peer-nominated and individually interviewed, provided an informal member checking activity.

With respect to *dependability,* presentation of the preliminary findings at two conferences (Hospice Palliative Care Manitoba, Winnipeg, Manitoba, September 2002, and The International Congress of the Care of the Terminally Ill, Montreal, Canada, 2002) elicited confirmation of credibility from a couple of participants as well as from other nurses in the field of transitional cancer care, including nurses from other parts of Canada, the USA, and South Africa.

The determination of *transferability* according to Streubert and Carpenter (1999) rests with potential users of the findings, not the researcher. If the study findings are deemed to be meaningful, transferability is more probable. Interestingly, at the same conference presentations mentioned above, several physicians and social workers provided feedback that the findings resonated with aspects of their experiences while caring for ILWPC. These professionals encouraged publication so that the findings could be extrapolated for their professional use.

Confirmability is the fourth concept of rigor described by Guba (1981), and Guba and Lincoln (1994), and is consistently cited in the literature (Polit & Hungler, 1996; Sandelowski, 1986; Streubert & Carpenter, 1999). Readings highlight the query about whether even an exceptional audit trail (i.e., recording of evidence of activities and thought processes that led to researcher conclusions) could ever be replicated. Certainly the very tenets of the uniqueness and subjectivity of qualitative inquiry causes some tension over the plausibility of confirmability. Morse and Field (1995) identify these same concerns in their discussion of rigor issues, noting that the emphasis of qualitative research is in acknowledging the "uniqueness of the human situation so that variation in experience rather than identical replication is to be expected" (p. 144). The debate leads this author to question whether this study could be replicated to the degree that all conclusions were exactly the same, particularly in the face of the uniqueness of the narratives shared and the ever changing nature of the context and environment in which cancer care is provided. However the integrity of the transcripts and observational notes has been kept, and exemplars and quotations shared in the findings to illustrate as clearly as possible the process and content that led to the delineation of categories and themes.

Multiple triangulation (two or more types of triangulation used in one study) enable the researcher to corroborate, elaborate, or illuminate the research in question (Marshall & Rossman, 1989, p.146), facilitating breadth, depth, greater accuracy, rigor and a multifaceted and comprehensive understanding of the phenomenon (Ingleton & Seymour, 2001; Streubert & Carpenter, 1999). Methodological and data triangulation have been used as a strategy to ensure comprehensiveness and rigor (credibility) of findings (Polit & Hungler,1996; Pope & Mays, 1999; Streubert & Carpenter, 1999). In this study, data and method triangulation were the two types that were chosen. *Data triangulation* in the form of *person triangulation* (Streubert & Carpenter, 1999, p.301), was planned for in a different way than was actually accomplished. It was hoped that more nurses who were less experienced in cancer care would volunteer for the first focus group in order to achieve data triangulation by collecting data from nurses at more than one level of competence. Though 3 nurses did so, the numbers were lower than hoped for in the original design of 6–10 participants for the first focus group. Further discussion of these potential limitations are discussed in Chapter Five. However, among all the participants there *was* variance in experience and how these nurses viewed their own level of expertise, as the demographics in Table 1 indicate. Thus, while some factors altered the original intent or expectations of the design for data triangulation, the resulting sample still represented a limited level of data triangulation and theoretical sampling.

Methodological triangulation refers to the use of more than one method to collect and interpret data (Polit & Hungler,1996), and was accomplished in this study through use of two modes of data collection:

- individual, person-centered, semi-structured, face-to-face interviews
- two focus group interviews—one with nurses of varying levels of practice

expertise (proficient to expert), the other with expert nurses.

With both approaches, contextual observations and reflexive notations were recorded by the researcher in alignment with the goals of person-centered interviewing and sensitivity to the interpersonal observations that occur during group interactions. The facilitator hired by the researcher recorded sociograms and written comments throughout the group interviews, and shared feedback in a debriefing process with the researcher, thus providing additional information that highlighted some of these dynamics in the focus groups.

The decision to use preliminary findings emerging from the individual interviews as central to the exploratory questions was used in the focus groups, and contributed to the rigor of the study. Having the research participants validate findings from the first approach provided a method of member checking, especially in that 3 of the self-selected group members had also been a part of the person-to-person interview process. This approach added to the trustworthiness of the results.

Purposive sampling, or the deliberate choice of informant-respondents (cancer care nurses) and setting (outpatient) based on pre-defined criteria (peer selection of 'expert' nurses), experience, knowledge and literature review, also enhanced the richness of information and understanding of the phenomenon being explored, providing rigor to the study design. Further explication of the sample and setting follow, and include discussions about this study's rigor and limitations.

Sample: Criteria, recruitment processes, and profile of participants

Qualitative researchers take the position that individuals who take part in research such as this study are not acted upon but are actually active participants (Morse, 1991; Streubert & Carpenter, 1999). That was the goal of this study. The informant-respondents were purposely selected because of their firsthand experience with the nurse-patient relationship in transitional cancer care, and the focus of inquiry was embedded in the complexities of that role. Sampling techniques in this type of study are used for the goal of obtaining rich or dense description rather than to support generalizability of the findings through probability selection, as one would do in a quantitative approach. The concept of purposive (or judgmental) selection is founded on the premise that the researcher is choosing the participants based on personal judgment. This decision is informed by prior knowledge and theoretical work likely to demonstrate salient features of behaviour relevant to the research question; and thus, about who will be most representative or productive (Patton, 1990; Polit & Hungler, 1995; Pope & Mays, 1999; Streubert & Carpenter, 1999).

Recruitment

Following initial contact by the researcher, letter(s) (Appendix C) were sent to the appropriate nursing leader(s) in the participating site, explaining the study purpose (Appendix D)and requesting the necessary site/institutional ethics approval. Once approval was achieved, access to the nurse managers of the outpatient cancer care services/clinics was sought in order to discuss approaches that were neither intrusive nor unethical in presenting opportunity for staff participation. Recruiting expert nurses for the person-centered interviews was done in conjunction with recruitment of volunteers for the focus groups, so that redundancy of time commitment of all parties was avoided. After the presentation of the purpose of the research in a staff meeting, nurses were invited to nominate their peers accordingly (Appendices E and F). Nurses who expressed an interest in participation, either as peer nominated experts or as self-selected volunteers for the focus groups, were contacted by the researcher and the study was explained to them more fully according to their individual needs so that any concerns or questions were addressed. (See section within this document on ethical approval processes, plus Appendices G, H, and I, for further information about informed consent and participant demographic and information forms. Appendices J and K provide copies of the notification letters of peer nomination and focus group participation. A study timeline is also provided in Appendix L.)

Since two approaches were incorporated into the methodological design, decisions about specific sample criteria and recruitment process are described separately in accordance with the differential processes for each group.

Person-centered interviewee selection

Purposive sampling of a target population of approximately 6-10 expert cancer care nurses from urban outpatient care settings of a provincial cancer care centre was planned. This is a number judged to be sufficient to uncover the descriptions required for this kind of study (Sandelowski, 1995). Quality of the data set is also paramount in determining the need to expand the sample. Redundancies and consistency of findings (Lincoln and Guba, 1985), hallmarks of "saturation" or the uncovering of no new information (Strauss and Corbin, 1990), indicate sufficiency of sample size to meet the study's aims. That is, a sample is deemed sufficient when "a deep ...analysis...results in a new and richly textured understanding of experience" (Sandelowski, 1995). In this study, consistency of the findings and similar descriptions of such things as the manner in which nurses assessed and identified patient readiness behaviours led me to judge that the sample size and quality of interview data was proving that it was achieving the study aims.

Of the original 15 peer-nominees, 4 did not respond to the invitation to participate, 3 declined related to other commitments, and 1 nurse withdrew related to health concerns, leaving the 7 individuals who were interviewed. Seeking a greater number of participants was not felt to be necessary despite the discussion of contingency plans for expanding the setting to include other outpatient settings in the health region. This had been considered, if the number of interviews was not achieving aims as anticipated.

Streubert and Carpenter (1999) discuss Morse's view of saturation, noting that "saturation" is a possible myth, concluding that the "best a researcher can hope for…is to saturate the specific culture or phenomenon at a particular time" (p.23). Saturation was thus evaluated according to the two major criteria described by Morse (1989) as *informational adequacy* (i.e., the sufficiency and quality of the data, assessed by looking at relevance and completeness—no "thin" areas exist, and the researcher is "not hearing anything new"); and, *appropriateness* (the degree to which the choice of informants and method of selection' fits the purpose of the study, the research question, and the stage of the research) (Morse, 1989, p.122-123).

Morse (1989) suggests that good informants are individuals who are knowledgeable about the topic by virtue of their involvement in specific life experiences, and are able to reflect and provide experiential information about the phenomenon under study (p.121). The implication of this to the choice of "expert" nurses for the informant role in this study is clear.

The nurses interviewed individually were peer-nominated according to the processes outlined in Appendix E. Previous research studies provided the framework for the exemplars given to nurses to assist them in the selection process (Benner & Wrubel, 1982; McClement & Degner, 1995; Raudonis, 1993), (Appendix E; see also Chapter 1, p.22 for definition and discussion of the concept of "expert," the background which led to the development of the process outlined). The three scenarios depicted "expert" nurse behaviours in communicating with individuals who need facilitation, support, and empathetic, accurate assessment of timely and appropriate nursing care.

Focus group volunteer criteria

The recruitment process of volunteer outpatient cancer nurse participants for the focus groups was facilitated by the researcher in collaboration with the participating institution. Forms for the self-selection of participants for the focus groups were distributed at the staff meeting and explanation of the study and process provided (Appendix F).

Each of the two focus groups were homogenous in that members were nurses who practiced in the area of cancer nursing. Diversity was based on their level of perceived expertise (from competent through expert, based on Benner's (1982, 1984) theoretical framework as outlined in the literature review), in order to provide greater scope of information gathering. The decision to have two groups of differing experience, but sharing the same focus on the nurse-patient relationship in transitional cancer care, was reflective of a special type of purposive sampling called theoretical sampling. Theoretical sampling involves selection of members based on emerging findings in order to ensure adequate representation of important themes, and to provide information-rich cases for describing the full nature of the phenomenon under study (Morgan 1998, v.2 in Morgan & Kreuger series; Patton, 1990; Polit & Hungler, 1995; Pope & Mays, 1999; Streubert & Carpenter, 1999). In accordance with advisement from the literature (Denzin, 1989, in Polit & Hungler, 1995), the use of multiple key informants about the same topic further enhanced triangulation (data triangulation), and thus credibility of the study.

One of the focus groups was comprised of nurses who volunteered because they were feeling the need to further develop confidence and/or expertise in facilitating transitional-palliative care, and the other of volunteer "experts." All participants were reflective, providing observant, articulate thoughts about their practice. Though some of these nurses (Focus Group 1 participants) may not have considered themselves to be as "expert" in knowing how and when to approach patients based on triggers of patient readiness, they were knowledgeable about their own feelings and shared insightful perceptions of the challenges that face them in entering mortal time. It was this comparable and contrasting awareness of the research question that the researcher sought from these informants. (Based on the "expert" individual interviews, inclusion of questions such as the following sample helped to probe for this information in the focus groups: "Some nurses have told me that__________; is this true for you?")

The goal was to limit each focus group to 4-10 members as the topic has the potential to be sensitive in nature (Morgan 1998, v.2 in Morgan & Kreuger series; Pope & Mays, 1999). Had the number of participant volunteers been greater than hoped for, more nurses than the desired group size were to be included in order to compensate for inability of some to attend due to weather conditions or other unforeseen circumstances.

As it turned out, both groups were small to begin with and from each session there was attrition of one participant related to personal circumstances with dependents. Strategies to encourage but not coerce participation were used, including a reminder call the day before the group was scheduled, scheduling the session at a time that was convenient for the participants in consideration of their work schedules, and by providing a meal or refreshments as determined preferable by the group. Despite these efforts the result was that only two volunteers participated in Focus Group 1, and four in Focus Group 2. Though Focus Group 1 (n=2) may have been better identified as a dyad interview, the label of "Focus Group" has been maintained because an interactive effect expected from focus group interviewing was maintained. The two nurses involved came from differing perspectives, exchanging ideas and challenging each other, while validating and confirming core concepts and tensions identified by the expert nurses who had been involved in the individual interviews. Both participants had also been a part of the face-to-face interview process; thus, they were able to provide a form of member-checking in the process of discussion.

Since sharing of ideas and experiences in a climate of mutual respect is central to focus group function, attention was paid to avoidance of differential authority lines, and to seeking compatibility of experience, practice, and interest in facilitating palliative care earlier in the illness trajectory (see Appendix F). Despite the small numbers, maintaining the two groups—rather than collapsing them into one larger group—enhanced attainment of this goal. All volunteers were accepted according to their common aim of desiring to improve interventions related to facilitation of transition to palliative care.

Participant attributes

Though demographic characteristics are of secondary value in qualitative research and are statistically non-representative, an assessment of demographics can provide data that are informationally representative. Hutchinson and Webb, in Morse (1989), note that demographic information can be useful and interesting, but "should not be provided under the pretense of statistical sampling" (p.293). Morse (1989) notes that though demographics have little significance, descriptive methods of describing the participants and the context should be used (p.128). That was the purpose in requesting demographic information (Appendix I) from the informants in this study. This approach is in keeping with person-centered interviews (Levy and Hollan, 1998), as well as Kleinman's (1992) explanatory models, and the goal of getting a "truer" picture of the attributes of the informant-respondent nurses enhances understanding of their social and emotional context. A number of "pie graphs" follow and have been used to give a visual summary of information provided by the participants on the "Participant Information Form" (Appendix I).

Figure 3 *Age of participants*

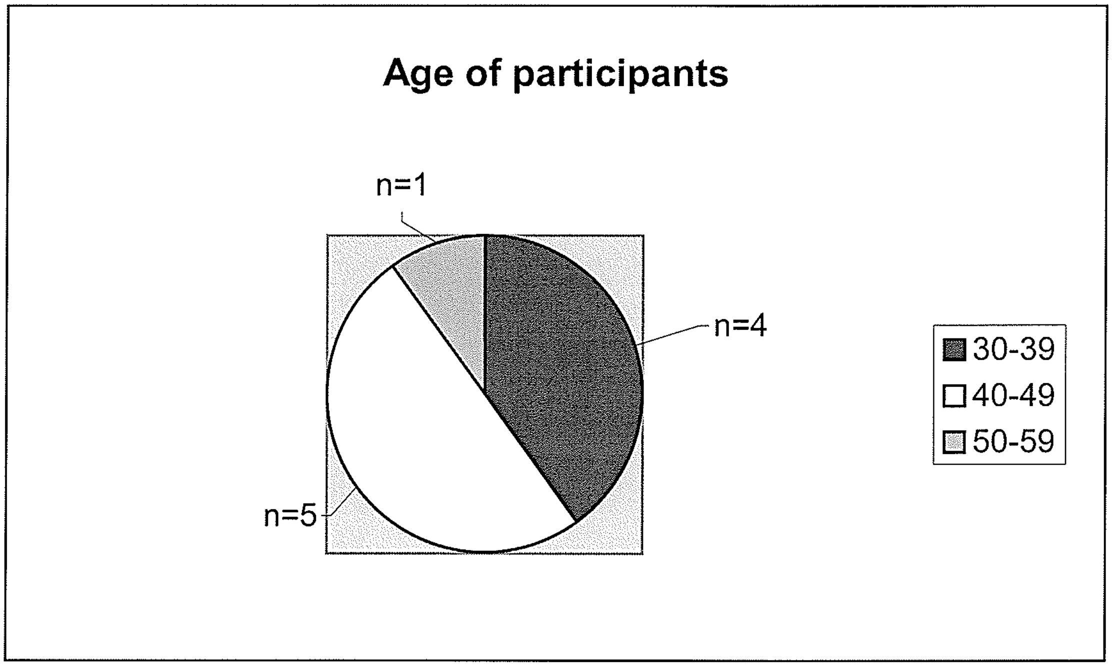


Figure 4 *Nursing education*

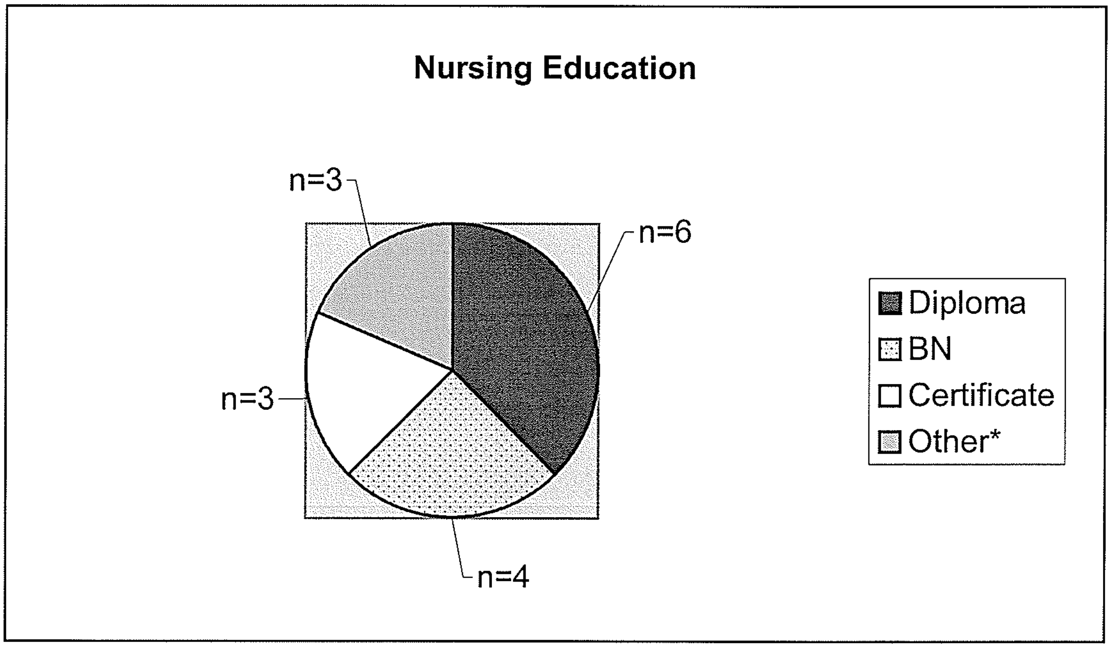


Figure 5 *Years of experience as a Registered Nurse*

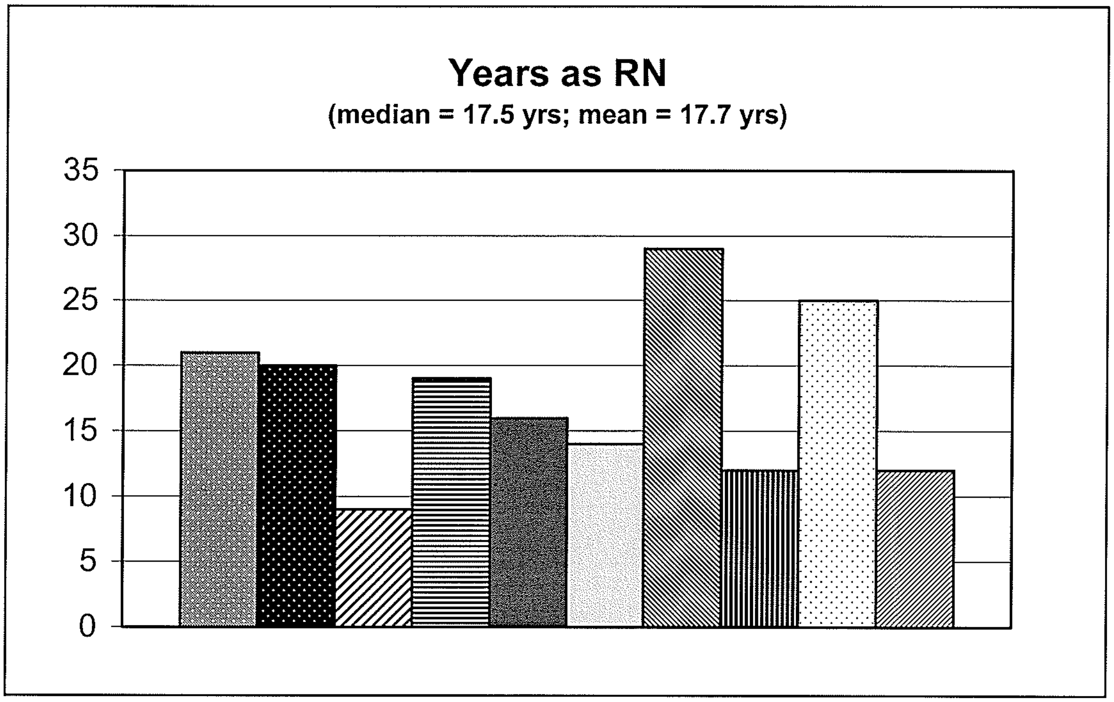


Figure 6 *Years of experience as nurse in cancer care*

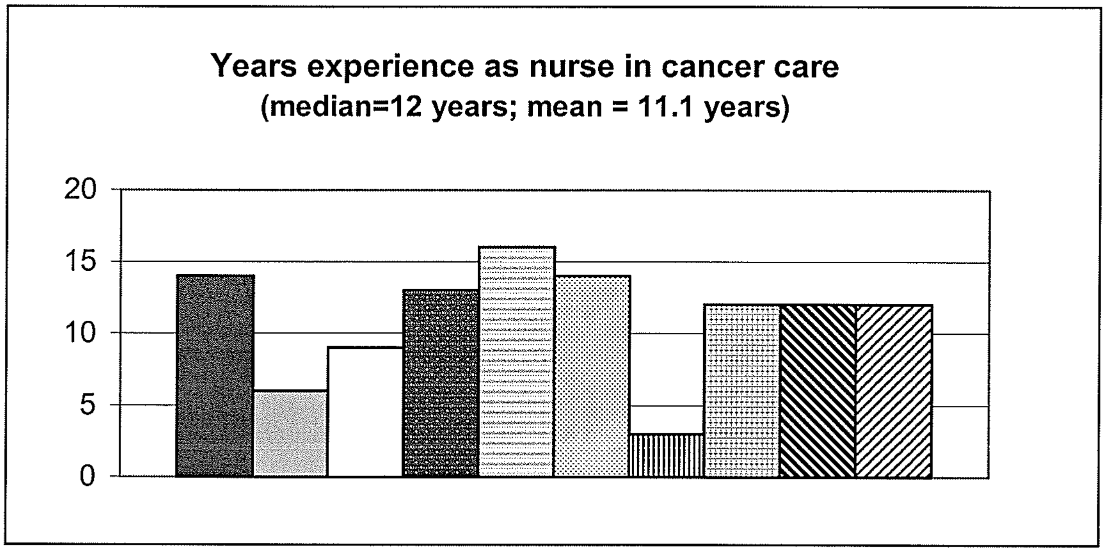


Figure 7 *Religious affiliation*

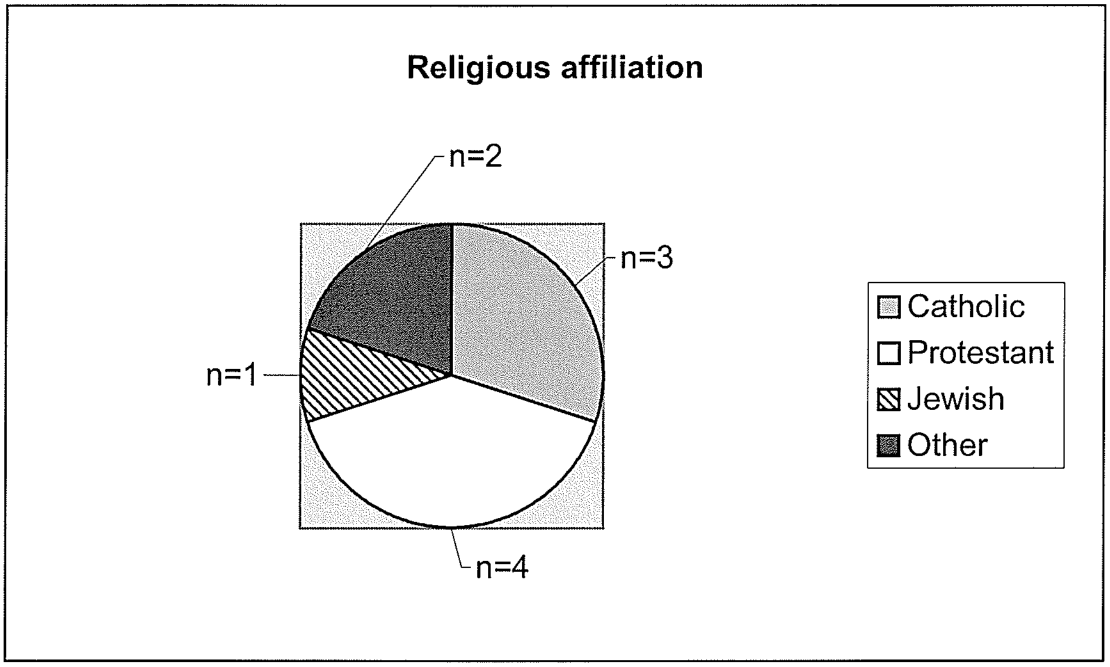
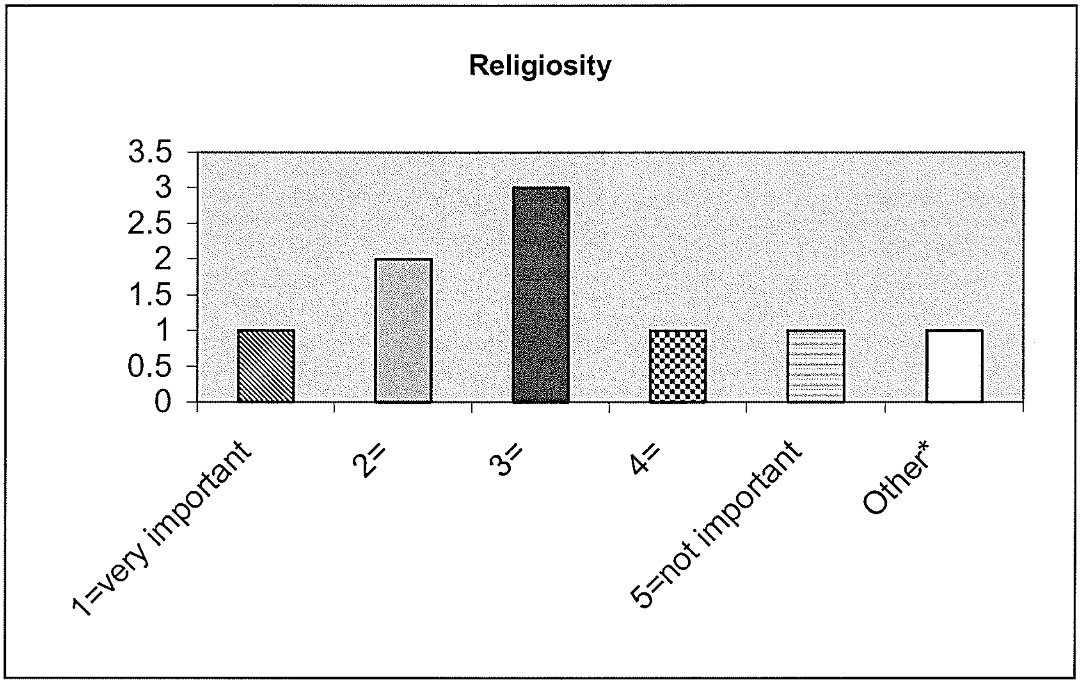


Figure 8 *Religiosity*



Sample size

The total number of 10 participants represented 18% of the total *possible* sample of the 55 nurses that work in this facility. Again, given the nature of purposive sampling and a desire in this study to access the nurses with particular expertise, ten nurses is a number likely representative of an even greater percentage of the available nurses that would meet the desired criteria. 15 nurses had been peer-nominated as "expert" in the matters of transitional cancer care. The sample size does not compare poorly with the numbers of participants in other qualitative studies (e.g., Kruijver, Kerkstra, Bensing, & van de Weil, 2000; Norton & Bowers, 2001; Ronaldson & Devery, 2001). As has been noted, importance of sample size is not numerically determined, but whether or not the research aim was able to be met.

Age and gender

As age ranges were requested (Appendix I), there is no mean or median age to report; but one can readily see from the graph that though the ages fell within the range of 30 to 59 years, the greatest proportion (n=5, or 50%) of the informant-respondent ages correlates with the general demographics of registered nurses in this mid-western province. The average age of nurses in the province in 2002 was 45 (College of Registered Nurses of Manitoba, 2002). One nurse was age 50 or more, and four were between the ages of 30-39. All nurse participants were female. (Of the two sites' total of 55 employed nurses, one is male.)

Religious affiliation and religiosity

The majority (8) of the nurses identified affiliation with a specific religion (4 Protestant, 3 Catholic, 1 Jewish). One nurse indicated "other" as her religious affiliation;

no nurses indicated the option of Muslim, agnostic or atheist, and another nurse indicated by written comment that while formal religion was not of importance to her, spiritual practices *were* of great importance. Her comment was noted, and she indicated "other" under the religiosity question. Religiosity was evaluated according to a Likert scale ranging from (1) "Religion is a highly important part of my life," to (5) "Religion is not at all important to me," on the participant demographic information form (Appendix F). Responses varied among the remaining participants, with 3 indicating moderate importance, and the remaining 4 nurses each singularly indicating the other 4 indicators on the Likert scale.

Ethnicity or cultural group

The nurse participants were asked to identify any ethnic or cultural group with which they identified. Two stated "Canadian," one "French Canadian," another Irish-Scottish Canadian," another "Irish-Dutch," one "Jewish," and four nurses left the entry blank. It was assumed that all were Canadian citizens given currency of their professional licensure within the Province.

Nursing education, length of nursing career and experience in cancer care

Six participants were diploma prepared nurses (one of whom had been a licensed practical nurse prior to becoming a registered nurse), 4 had a Bachelor of Nursing degree, one nurse had a Master of Education degree, and another was enrolled in graduate nursing studies. One nurse indicated that she held a certificate in applied counseling.

The median number of years in the nursing profession as a Registered Nurse was 17.5, and the mean 17.7 years, with a total of 177 years of nursing experience represented. The median number of years as a nurse in cancer care was 12, with the average or mean being 11.1 years. The total number of years of experience in cancer nursing represented by the participants was 111 years.

Personal comments and experiences with significant losses

The participants were asked for any comments on recent change(s) in their work environment that might help, detract from, or influence their nursing practice in any way; and eight participants did make comments. The question was asked in keeping with the framework of explanatory models in order to provide any additional insight into the contextual factors of the nurse participants' perceptions, beliefs or values, or significant influences on their practice. Several noted the dynamics of increased workload intensity with staffing shortages, less space, and less time available to spend with patients. Two identified recent changes in their responsibilities from direct care provision to management. Two others noted changes in their work from inpatient to outpatient services in cancer nursing, and another noted a change from a mixture of caseload as a community nurse caring for both cancer and non-cancer patients to now exclusively caring for individuals with cancer. Only two of the nurses had been introduced to cancer nursing in their current organization, the setting for the study. One nurse noted an increased awareness of palliative care resources in the organization. With the exception of one nurse, all indicated that they had experienced the death of someone close to them, including losses of pregnancy (multiple for two participants), parents, sibling as a youth, grandparents, aunts and uncles, close friends and a mentor. Many noted their losses had been multiple, others noted the nature of the loss, including cancer, accidental death, suicide, and miscarriage. The person who had not experienced loss from death had experienced painful estrangement from a parent and noted the monumental grief process that has accompanied that loss. The range of years from the time of the experience was from very recent (within the past year) to 23 years ago. Some nurses had experienced more than one death of persons in close relationship within a period of several years. One nurse had lost a parent to the form of cancer for which she was now involved in caring for others. The profundity of the multiplicity of losses personally, in addition to those experienced by virtue of their work, was striking to me.

Settings

Setting of nurse participant practice

Qualitative research uses the "field," or the place where individuals who are the participants live and experience life (Streubert & Carpenter, 1999). This study involved nurses from various outpatient cancer clinic sections in two different tertiary care facilities which function under the auspices of a single provincial cancer center located in a major city of a Canadian prairie province. The outpatient setting provides patient visits that are typically scheduled (though some are not scheduled), within appointed time frames, with the purpose of the visit dominating the agenda. A portion of care may be provided by telephone contact. Appointments may be made for diagnostic assessment/intervention, treatment decision making, treatment, follow up assessment from treatment and/or other interventions and diagnostics, teaching, counseling, and referral processes. Spaces are allocated for waiting, assessment, treatment, and counseling or conferencing with families and members of the care team, and a central area for reception and clerical follow up of appointment scheduling dominates the waiting areas. Nursing documentation and phone call areas are generally less in the public area, and thus do afford some privacy and ability to maintain confidentiality.

One of the sites had recently undergone major reconstruction, including the construction of an additional new building; but some clinic areas were already expressing the need for more space to accommodate the necessary care. The second site was also experiencing some renovation at the time of this study and space was often at a premium. Though attempts made to create comfortable waiting environments with pleasant colours, furnishings, lighting, available refreshments, and volunteer presence, had been successful, many patients have indicated that the waiting time is difficult because of anxiety, fatigue and other symptoms they may be experiencing as a result of either treatment side effect(s), and/or disease progression. There is a pervasive sense of busyness in some of the clinic areas, an awareness of the numbers of individuals receiving cancer care. Patients in this setting and in others reported in the literature (Singer, Martin, Lavery, Thiel, Kelner, Mendelssohn, 1998) have commented on how that perception impacts their felt need not to consume too much of the time of the professionals involved with their care. These are significant influences on the time provided for transitional and/or existential issues.

Given these factors and a need to better understand the complexity of the transitional period of living with progressive cancer, influenced the setting choice of ambulatory or outpatient care. Much of the cancer care trajectory where treatment decision making and nurse-patient interactions are occurring happens in this setting. Yet most of the literature has focused on the inpatient setting, and later timing in the process of transition. Furthermore, it is often the case that nurses in the outpatient clinic setting are able to establish relationships over time with patients and families. Thus they are even more aware of the nuances of individual patient behaviours that may indicate readiness for discussion of issues, existential or otherwise, that are an integral part of transition from curative to palliative goals of care.

Settings for the interviews

Interestingly, Pope and Mays (1999) point out that since the setting of an interview affects its content, “it is usually preferable to interview people in their own homes” (p.18). In respect for participant autonomy, however, the individual, face-to-face person-centered interviews for this study were held in a location of the nurse’s choice. No participants chose to meet in their homes, and though one nurse did offer her home as a location for the first focus group, the participants declined that option. Settings were arranged to enhance convenience for the participant. Most of the participants chose to meet in a quiet location within their own institution (i.e. a conference room or their office) either before, during, or at the conclusion of their work day; one chose to meet in a room at the provincial nurses’ association building on a day off, another in an independent college setting close to her home on a day off. Whatever the choice of the respondent-informant, attempts were made to consider and respect the following: their time commitment (information about travel/parking or child care reimbursement if needed, length of anticipated time needed for the interview); comfort (seating, space, temperature, lighting, placement of tape recorder, maintenance of privacy, safety, and a light snack or meal); and a minimization of distraction. Enhanced focus, freedom of expression, trust, respect, and minimization of participant anxiety were the hoped for outcomes of these considerations. Generally these conditions were able to be met. A few exceptions occurred and these are discussed in Chapter Five in association with possible influences on process learning, and even potential limitations on the findings.

The same considerations were adhered to for the focus group settings, with mutuality sought and achieved among the participants in regard to choice of location. Both groups met in a comfortable conference room with access to amenities for the refreshments, and where windows allowed natural daylight to filter in. In accordance with the wishes of the participants, Focus Group 1 was planned for at the completion of the work day, and Focus Group 2 during the work day over an extended lunch period.

Data Collection and Data Management

Access

Access to the participants is a critical step to the data collection design (Streubert & Carpenter, 1999), and appropriate steps for researcher access were taken. Initial contact was made with both the Provincial Director of Patient Care Services and the Director of Nursing, followed up with correspondence (Appendix C, letter of request for research access) and an executive summary of the project (Appendix D). Interest in the project was expressed and the required processes for institutional ethical review and resource impact assessment started. Once approval through the Education and Nursing Research Ethics Board of the University of Manitoba and the Institutional Resource Impact Committee of the provincial cancer care institution was achieved, a meeting was set up with the nurse unit managers of the outpatient staff to determine detailed logistics of sharing information about the study and the peer nomination and consent processes (Appendices A, E-I). Steps were taken to ensure that staff unable to be at the initial information meeting still had access to the information and peer nomination forms. Information about how to access the researcher was included in the process and on each form, with the invitation to contact the researcher if there were any further questions or concerns.

In order to enhance confidentiality, staff were requested to mail their completed peer nominations in a sealed, addressed, stamped envelope, supplied by the researcher. A two week period for mailing was suggested, and a personal visit arranged to come to both sites of the cancer center to allow any further questions of staff. A poster reminder, on the nurses' email system, which all nurses have access to, was also provided by the researcher. Once the nominees were peer selected they were contacted by phone and /or email according to their preference and opportunity for further explanation and agreement to participate elicited/confirmed. (Nurses who had not responded in any way were given a second opportunity by email to participate in the focus groups, but none did so.)

Prior to each interview, the consent form (and explanations) were again provided, along with the demographic form, for completion and collection. Forms regarding confidentiality were also signed by the transcriptionist and the focus group facilitator. The respondent-informant nurses were the primary source of data in this study, with the researcher being the primary research instrument. Data generation and management was done in accordance with ethical principles that are discussed toward the conclusion of this chapter. The following section outlines further procedures for data collection and management for each of the methodological components.

Person-centered interviews

In-depth, face-to-face, individual interviews guided by core questions based on the study objectives and the literature review (Interview schedule-Appendix A) were completed over an average of an hour with seven participant nurses. The order in which questions were asked sometimes varied according to the natural flow of parts of the interview, something Pope and Mays (1999) note as typical for semi-structured interviews. There were occasions, for instance, when questions arose out of the content of narratives and researcher probes for the meanings intended by the respondent-informant were elicited. There were other times when the participant provided information that covered subject matter related to more than one question. As the interviews progressed, and as the interviewer became more skilled and familiar with the subject matter elucidated by the participants, the interview guide questions were refined to better explore and delineate the complexities of the inquiry. Interviews were audiotaped, and transcribed verbatim. A clean copy of each interview has been kept and stored untouched, along with the original tape recording in a secured file.

Focus Groups

Data collected from the two focus groups were also audio-taped, transcribed verbatims of the group interviews. In order to generate discussion, an early draft depicting the transitional cancer experience was provided, along with a description of the concept of "mortal time" reflecting some of the findings (e.g., quotes/categories) and tensions from the individual person-centered interviews. Though a video clip of poignant patient statements concerning the experience of progressing illness was brought for use at the beginning of the session to stimulate reflection about the nurse-patient role in such circumstances, this tool was not used according to group consensus. That is, the group felt that option was not needed and that it might cut into discussion time. The secondary purpose of such tools to encourage participants to focus on the research question and each others' perspectives rather than on the role of the leader (researcher) and facilitator was not necessary as the group members were highly motivated by their own interest in the subject matter and the nature of the questions. Focus Group 1 responded to the initial questions and brief summary of some of the initial findings, one having already been a participant in the individual interview process. Focus Group 2 felt that the diagram provided (proposed model of transitional cancer experience) and the questions raised by the individual expert nurse participants was provision enough to get them focused on the questions at hand. In this group also there was a nurse participant who had been peer-nominated as an "expert," and individually interviewed, so her presence also provided an element of "member checking" in the process of the group interview.

A clarifying review and summation on a flip chart of content themes that had emerged during each focus group was provided at the conclusion of the session. It was led by the facilitator according to her hand-written observations, to provide an opportunity for validation and member checking. Participants were also invited to speak with the researcher and/or facilitator in privacy if they felt the desire or need to do that. No participants indicated that need, though a number did indicate after the session that the experience had been personally gratifying and "cathartic" or "therapeutic," and all participants indicated their feeling that as nurses "we need to do this more often" (personal reflections and observations, May, 2002). Participants gave consent for their untaped feedback as interaction to be included in observational data.

The tapes, transcripts and other documentation that composed the data collected from the focus group interviews have been managed according to ethical principles of confidentiality and all originals (disks, tapes, paper transcripts, code books and researcher journal, transcriptions and observational notes) have been kept intact, and working copies created.

Observations and reflexive journaling

Data were considered in the light of researcher notes about contextual observations, feelings, and thoughts noted after individual and group interviews. Ensuring that differences or disagreements were explored and points of view elucidated and clarified, the focus group facilitator produced some additional notes related to group dynamics (i.e., sociograms), attitudes, and processes including nonverbal behaviors and other contextual factors influencing and/or coming from the flow of discussion. (It was most helpful that she had done so because a portion of the end of Focus Group 1's first tape did not come through on the tape recorder, a fact unknown until after the interview, as earlier testing had demonstrated that the recorder was working well.) The facilitator then took her notes and transcribed that last 15 minutes of the interview that evening as well as she could retrospectively, and they were reviewed the following morning by the researcher for accuracy of recollection of the significant points made by the participants. These observations, in collaboration and debriefing with the researcher, have been integrated into the summarization of the group's interactions and used as part of the data collection. Reflexive journal entries and miscellaneous notations kept by the researcher were reviewed and have added to data analysis, and discussion in Chapter Five. Copies of the audio-tapes were made immediately following each interview. The original was kept by the researcher, and the transcriptionist provided with a copy that was returned upon completion of the transcription.

Data management and analysis

As is the case in much qualitative research, the researcher used reflection and analysis from the beginning of data collection as it was impossible to ignore what is seen, heard, and experienced during the interviewing process (Polit & Hungler, 1995, Streubert & Carpenter, 1999). Streubert and Carpenter describe the intense commitment the researcher feels towards the data as being “immersed” or “dwelling with” it. A process of reading, re-reading, intuiting, analyzing, synthesizing and then reporting the discoveries, highlights what these authors mean about “dwelling” with the data (p.28). That process truly became my lived experience, as each interview took place and was coded, reflected upon again and again, and then integrated into the accumulating data.

Classic content analysis involves quantification of aspects of written materials (Holsti, 1969; Polit & Hungler, 1995; Pope & Mays, 1999). However as noted by these authors, a variant of qualitative content analysis of narrative data to identify prominent themes may also be used. Qualitative content analysis was used for this study, employing suggestions from several authors to form the procedural framework (Holsti, 1969; Morse, 1989; Polit & Hungler, 1995; Pope & Mays, 1999; Streubert & Carpenter, 1999).

Boyle, in Morse (1989) suggests that as soon as possible after the interview, transcription should be done and the transcript then read by the interviewer while listening to the audiotape. This exercise permits familiarity with the data and early identification of errors, or unclear/ incomplete portions of the tape. Any such concerns should be addressed before coding begins, and may even require a call to the participant. These recommendations became a part of the approach that I used. I received the transcripts from my transcriptionist in an extremely timely manner, generally well within one week of the interview. The transcript was then reviewed with the audio tape to ensure accuracy. In one situation I did need to call the interviewee to clarify a procedural acronym used in bone marrow transplant procedures that I was unfamiliar with. In another situation the auditory function of the equipment was lost early in the interview. What turned out to be technical failure of a microphone attachment—originally assumed by me to be a result of technical incompetence—was not picked up by the researcher and participant as testing of the equipment at the outset had proved to be satisfactory, and the tape was apparently running as it should during the interview. Follow-up with the participant to explain the situation led to her gracious willingness to repeat the interview, and that was done within a couple of weeks of her original time. Otherwise all other transcripts were clear and able to be accurately understood.

According to Polit and Hungler (1995), the content analysis of qualitative data usually begins with a search for themes or recurring regularities (p.527). The semi-structure of the interview schedule (Appendix A) provided some basis for thematic analysis. The data were thematically coded or "indexed," to clearly indicate that coding in the classic form (quantitative) was not being done (Pope & Mays, p.78). Rather, it was done manually indicating a "hands-on" approach to working with the data. (Other than word processing techniques, computer software programming specifically for managing qualitative data was not used. This decision was based on the view that though such approaches are a "convenient means of coding and sorting data," it in no way "substitutes for the rigor and creativity of the researcher" (Morse, p.269).) This "hands-on" approach was encouraged and endorsed by my advisor. Analysis, as described by Morse (1989) and Wilson (1985), proceeded through the stages of:

- open coding in the margins of the transcripts

- developing a rationale and illustration to guide the coding of data into categories
- writing codes on cards (I started with a system of semi-adhesive notes and eventually used various colours to help me group related categories as they were emerging)
- category building (which were detailed, mutually exclusive, and defined as clearly and fully as possible with attention to common antecedents, attributes, and consequences)
- category saturation (i.e., when no new information on the characteristics of the category was forthcoming).

Wilson (1985) describes coding as the process of conceptualizing the underlying patterns in a set of empirical indicators (p.418). A code catalogue was created on the computer to document the definitions for various categories used to code or index the data. I compared the content interview by interview, and category with category in the data. Comparison of similar data enabled me to define the basic properties of categories, and the context under which the category existed. As suggested by Streubert and Carpenter (1999), each category was then compared with every other category to ensure that the categories are mutually exclusive.

Polit and Hungler (1995) note that themes often develop within categories of data, but also sometimes cut across them (p.527). Given the complexity of the subject matter in my project, there were times when the attributes of particular categories were less clearly able to be teased out in a truly distinctive or exclusive manner. Thus Polit and Hungler's advice that attention must be paid to not only the themes per se, but also to how they are patterned, or relationally situated within the data was important for me to keep in mind. Scrutiny of clearly deviant or negative information was integrated into the analysis procedures according to the guidance of Pope and Mays (1999), who note that such discernment can contribute to refinement of the analysis, and counteract any preconceptions or assumptions

All categories were reviewed by the researcher's advisor, a process that assisted with confirmability of the evolving categories. Such peer review is recommended by numerous authors (Ingleton & Seymour, 2001; Polit & Hungler, 1995; Pope & Mays, 1999; Streubert & Carpenter, 1999). The identified categories, were also reviewed with the focus groups, and since there was overlap of three individuals from the individual interviews in the two focus groups, there was an informal process of interviewee member-checking that the thematic analysis to that point had been an accurate representation of their contributions and perspectives. Participants were thus given opportunity to add, delete, or modify their contributions within the context of the group interview.

In view of the novice level of the researcher, early transcriptions were also reviewed by the advisor to elicit feedback on need for modification of interviewing skills to better maintain the integrity of the research study questions. The hired facilitator provided helpful feedback after the first focus group, and honing of researcher skills for Focus Group 2 enhanced the process. The facilitator's feedback during debriefing and the transcript comparison of the two groups demonstrated improvement of the researcher's skills.

Unique considerations regarding focus group interview transcript analysis

Major themes that presented in both groups were analyzed in keeping with qualitative analysis procedures. Pope and Mays (1999) indicate the need to take full advantage of the interaction *between* participants as well as analyzing the *individual* contributions, because examination of sensitive moments in the group dynamics may provide significant information. This may be particularly true if participants have identified quite different perspectives, and if explanations for those differences are explicated among members. This proved to be important in the groups, and there were times where the participants themselves were able to provide the probes needed to explore matters more fully (e.g., "How did you feel?", FG2R756; "If I could just go back to …," FG2V868 & FG2S940). Analyzing focus group material included searching for particular types of interactions, such as jokes to relieve tension, censorship, challenges or changes of mind. In the two focus groups of this study, there was an empathy for the deeply felt and expressed emotions of each other. In one group there were moments of tension related to some polarity of views; but that polarity was significant in that it reaffirmed the tension expressed elsewhere about how and when the subject of palliation may be introduced. Pope and Mays stress that these codes are key and need to be as inclusive as possible (p.79). The keeping of clear observational notes after the focus group was helpful to the analysis process, as was suggested by Morgan and Kreuger (1998). They also recommend the adherence to qualitative analysis procedures, the depth and complexity of which were relevant to the purpose and aims of the use of the focus groups and findings.

Observational data (e.g., reflexive journal entries) associated with the individual and focus group interviews were also integrated into the findings by seeking relational connections to the descriptive analysis. In the final stage of analysis, themes from all three sources of data analysis (person-centered interviews, focus groups, and observations) were integrated and synthesized into a meaningful "whole." Polit and Hungler (1995) note the level of extreme difficulty with this task because it demands creativity and intellectual rigor. Again, this final stage was reviewed with the researcher's advisor in order to enhance trustworthiness of the process and findings.

Limitations

The following potential limitations are placed upon this study.

Firstly, the purposive sampling approaches used may raise issues about the question of transferability (fittingness), and some of these considerations have been discussed in defense of the choice of methodology. While qualitative approaches do not enable generalization of findings beyond the sample, many of the concepts emerging from this work may be transferable, with cautions and caveats, to other clinical situations. Further research will be needed to confirm the degree to which this model might be felt to be transferable to nurses caring for other patient populations (e.g., transitional care of persons with other chronic illnesses); they alone must determine that from the data base as has been pointed out (Lincoln & Guba, 1985; Sandelowski, 1986; Streubert & Carpenter, 1999).

Secondly, there may be under- or over-representation of certain groups of individuals within the sample, but these limitations could not be determined in advance. The sample certainly represents a broad range of clinical expertise and roles within the given setting itself. The size of the sample, particularly for the focus groups, could be considered inadequate; but, as a purposive sample of nurses it was not chosen to be fully representative of the population of nurses in the cancer care institution. Some participant nurses were selected by their peers because they were perceived to be "expert," and some were volunteers wanting to contribute to a focus group process that was attempting to explore and describe the complex role of nurses in transitional cancer care. It is acknowledged that the potential benefit of theoretical sampling was not accomplished to its full extent as planned. A limited number of participants volunteered for Focus Group 1 which was to have been composed of nurses who had self-selected based on their perceived level of clinical competence as being less than "expert" (i.e., "proficient" or "competent," according to the provided criteria according to Benner (Appendix F)). Interestingly, three peer-nominated nurses who had been individually interviewed, also volunteered to participate in the two focus groups, an unexpected but serendipitous happening. Their presence provided a means of member-checking that strengthened the rigor of the study. The down side that might be argued, however, is that then the thoughts of 10 nurses only were "tapped."

However, the input was still rich and the dialogue representative of tensions about some issues such as timing of intervention, that were articulated but not as deeply explored in the singular interviews. There were indicators of saturation because there were repetitive codes, categories and then themes that emerged in the discovered information. Some data confirmed aspects of other studies and the general literature that is ever emerging related to the complex phenomenon of transitional cancer care and the attributes of care that ILWPC indicate are important to them in the shared management of their care. (More of this is discussed in Chapter Five.)

The role of researcher as the tool, with the inherent potential for personal world view, experiential and attitudinal bias to influence the direction of interviewing is acknowledged as a third possible limitation. Certainly researcher inexperience is admitted. However, strategies of keeping a reflexive journal and observational notes, employing the expertise of the thesis committee (especially in early phases of the study development), seeking early feedback on initial interviews to monitor interviewer influence on data collection, having the advisor also review the analysis of data, keeping a set of the transcripts and tapes intact to enhance accountability for accuracy, and employing a facilitator from outside the field to assist with the focus group interviews, all worked together to minimize the negative effects of researcher inexperience, subjectivity and bias.

Levy and Hollan (1998) note that the level of researcher awareness of the language and experience may be optimal or not in relationship with respondent-informants. Two perspectives need to be acknowledged as a potential influence on this study. Given the nature of the research question, a basic level of commonality in understanding some of the language and experience of care seemed to put the interviewees at ease. Empathy in the context of shared knowledge facilitated disclosure. An interactive interviewing style was deemed appropriate in the circumstances; that the researcher was at times emotionally responsive (e.g., the transcripts and researcher observational notes indicate times of laughter and I know there were tears of empathy that came to my eyes on occasion) was a human response, not used with any intention of swaying the data. If emotion acknowledged taints the data in any way then I must acknowledge that as a potential limitation. Conversely, however, it could be argued that to have *no* emotional response with such deeply felt sharing of experiences, there could also have been a "shut-down" of mutual respect and in losing trust, the participants may not have felt free to be as real about their lived experiences.

Differences in experience, settings of work and roles, however, facilitated the exploration of knowledge and perspectives so that the explanatory models that nurses were using could be probed further, and any undiscerned assumptions—on the researcher's part particularly—be challenged.

The final limitation reflects the acknowledged complexity of transitional cancer care, and that the singular study of the nursing role lacks the necessary comprehensiveness of approach to provide trustworthy results in better understanding the multifaceted nature of the experiences of progressing illness. Though there could potentially be benefit in researching the multiple perspectives of patients, family members, and other care team members in articulating the dynamics of this complex illness trajectory, it has been felt that looking at a significant perspective, that of the nursing role and the contributions nurses' work makes within that complexity was worthwhile in beginning to illuminate at least this one dimension of a matrixed health care challenge. The breadth and depth of the literature review in providing a comprehensive interdisciplinary and patient-sensitive context for the nurse-patient role has helped to minimize the impact of this potential limitation. Certainly the need for more extensive research is recognized.

Ethical considerations and the protection of human subjects

This research study was conducted in accordance with the standards set out in the <u>Tri-Council Policy Statement: Ethical Conduct for Research involving Humans</u> (1998) and with the guidelines and protocol requirements of the Research Ethics Board of the University of Manitoba. Requirements of the institutional Resource Impact Committee were also met prior to the onset of the research process. The appendices for theses processes are included for reader review (Appendices A-K).

Participants who met the criteria and agreed to be contacted were approached by the researcher after the purpose, procedure, and voluntary nature of participation in the interview and focus group methods were explained in two general staff meetings arranged with the collaboration of the unit nurse managers. Related ethical principles and guidelines were clearly reflected in the two-part consent forms (Appendices G and H). Written, informed consent was obtained immediately prior to commencement of each face-to-face individual interview (Appendix G) and for each participant of the focus group interviews (Appendix H); the participants had received their own copies of these forms several weeks in advance of the actual interviews so that opportunity for clarification of any concerns could be addressed in advance of their participation, as well as at the time of the interview. Mutual agreement regarding the setting and timing of the interviews, as well as careful consideration of the maintenance of privacy and confidentiality in the setting were ensured. Participation in this research study was voluntary; the participants were informed of their choice to refuse to take part and that withdrawal at any time, without penalty, was also their choice, along with the option to decline answering any particular question or line of questioning. Discussion of potential for burden and/or benefit was included in the consent process, and specifically delineated on the form so that participants had personal copies of the information.

Participants were also informed of the measures to be taken to preserve confidentiality of the information, and they chose their own pseudonyms. Appropriate steps have been taken to ensure that maintenance of confidentiality of all data has been maintained. Data has been reported and described in a manner that will preclude identification of the source. Codes for each interviewee and focus group participant were created, matched, logged and stored in a locked filing cabinet accessible only to the researcher during the process of data management and analysis. The log book will be destroyed at the completion of the study requirements. All data that was generated, including tapes, transcripts, and observational notes have been coded and kept in a separate, secured location, and will be retained for up to ten years following the conclusion of the study. Participants will be receiving a copy of the results according to their expressed wishes. A bound copy of the thesis will be donated to the library of the participant institution.

Conclusion

In summary, this chapter has outlined the rationale for use of an exploratory, descriptive qualitative research design to answer the research questions about the nature of the outpatient cancer nurse role in transitional cancer care.

Strengths of the research design were explicated, including the exploratory and descriptive detail of meaningful articulation of complex, subjective, value-laden social processes, the active participation of expert nurses (as well as of a few nurses who self-identify as being "proficient," or less "expert" than they are striving for in practice) in the collaborative research effort to give voice to their practice, multiple triangulation and other methods of establishing trustworthiness. The sample of cancer nurses, those eligible participants as peer-nominated experts or as volunteers for the focus groups, has been described, along with the setting—a Canadian prairie provincial cancer care outpatient service—and how it was used.

Potential weaknesses and limitations related to qualitative research, both generally and specifically related to this study's design, have been also been discussed. The processes related to data collection and analysis for each of the methods—person-centered interviews, focus groups and observational and reflexive strategies have been described in relation to qualitative content analysis procedures. Adherence to ethical principles and respectful processes have all been identified with reference to the appropriate appendices which explicate procedural details.

CHAPTER FOUR

SHARING MORTAL TIME: THE FINDINGS

Introduction

Findings of the study are presented in this chapter, with attention given to the research questions that shaped the semi-structured interview guide (Appendix A). A framework for explication of the themes and categories illuminated by analysis of the interviews is summarized in Figure 11, (p.118) and presented at the outset of the findings.

A synthesis of models about the transition experience of individual(s) living with progressing cancer (ILWPC)(Appendix B), is also described and discussed. This composite model was developed from the descriptions and narratives of the nurse participants about their observations of both patient experiences with transition and the responsive role of the nurse (Appendix M). Though the goal of this study did not *directly* involve ILWPC, aspects of the conceptual diagram are based on a number of sources. Sources, highlighted in the review of the literature (Chapter Two), include direct narrative information gleaned from numerous patient accounts of living with progressive illness—both in formal research studies and in personal anecdotal literature—(e.g., Gregory & Russell, 1999; Kuhl, 2002; Mayer,1998; Öhlen, Bengtsson, Skott, Segesten, 2002; Simmons, 2002; Tefs, 2001), along with participant narratives about their observations of patient responses. The latter are integrated throughout this chapter. The depiction of transition has been developed as part of the research process and offered as a part of this study to help describe the complex matrix of contextual influences on the work of nurses in transitional cancer care.

The illuminating power of narratives in the nurses' attempts to articulate the nature of their work in transitional cancer care is further enhanced by the metaphor of "storying" (i.e., the process of creating, telling, relating and listening to accounts of facts, events or experiences that deserve narration). The terms "narrative" and "story" are interchangeable. Similarities, differences and sources of tension inherent in the nursing role are described by the participants and supported with exemplars as appropriate. Such findings illustrate the inherent complexities acknowledged in Chapters One and Two, and implications are further discussed in Chapter Five.

A final note of introduction to this chapter is warranted. Though six distinctive themes, along with their supportive categories, emerged from data analysis, there was certainly tremendous challenge in teasing out some of the finer and more complex dimensions. Many are intricately interconnected phenomena. While any given phenomenon may have found its categorical home within a particular theme, it is likely to have additional significance within another of the themes. In other words, while there are genuine differences between categories, there are also connections within and among the categories. Notation is included where there are such interrelationships of categorical information. However, attempts have been made to classify phenomena according to their most salient attributes in order to be as respectful as possible to the integrity of the data.

Presentation of the Findings. Sharing mortal time: the experiences of nurses in transitional cancer care

To protect informant–respondent anonymity pseudonyms given by the participants are used throughout the document. Verbatim interview quotes are referenced by the first, or first two, initials of the pseudonyms. Focus group participants are identified as participants in either the first or second group with the capital letters, FG1(Focus group 1), or FG2 (Focus group 2), then the appropriate initial, followed by the line number from the transcript (e.g., FG2J103). Most of the researcher interjections such as "(m-hmm)," or "(Yes)" have been removed for the sake of brevity; and some of the repeated phrases or words that happen in spoken language (e.g., that....that...that; sort of, you know, like) that offer little enlightenment, but tend rather to encumber reporting of the responses or information offered by the participants have also been edited out. Remarks regarding voice tonality or emphasis have been left intact in the spirit of person-centered interviewing. Italics represent speaking-participant emphasis; strongly emphasized words are indicated by "(emphasis)," or descriptions such as "(rising inflection)," after the fact (e.g., "they're a little bit more *accepting* (emphasis)"). Words or phrases in square brackets (e.g., had she [the physician] not encouraged...), indicate editorial insert to assist with flow or explication of language; and three successive dots (i.e., ...) indicate either a pause, or that a sentence or fragment between quoted portions has been eliminated such that textual meaning was not affected. In all other ways I have reported the data as provided and it has been my goal to maintain the integrity of meaning within the context of intent.

Six major themes emerged through data analysis. They are divided into two sections, Part A and Part B, to denote their distinctive contributions to the framework. A summary figure of the themes follows and frames the discussion. The acronym ILWPC (individual(s) living with progressive cancer) is used in the figure.

Part A: Narrative Framework	Hearing Story	Interpreting story	Supporting story: setting the scene	Participating in story: facilitating transition
Themes	A1. Presencing and respecting personhood	A2. Discerning readiness: broaching issues of mortal time	A3. Preparing for mortal time	A4. Sharing mortal time: processing and facilitating awareness
Categories	A1.1. Listening and hearing A1.2. Weeping with A1.3. Connecting with A1.4. Respecting personhood A1.5. "Being with" while "doing for"	A2.1. Grasping the situation A2.2. Reading readiness cues and feeling your way A2.3. Paying attention to contextual factors: age, gender, religious faith and culture, social family dynamics, nurse-patient relationships, and systems/ organizational influences A2.4. Interpreting meanings and use of language	A3.1. Gathering and integrating facts A3.2. Relationship building A3.3. Opening the door and using opportunities A3.4. Teaching and normalizing	A4.1. Turning the corner: processing transition and mortal time awareness A4.2. Coming alongside: facilitating transition

Part B: Meta-framework for the narrative	Enabling integrity of story	Creating spaces for new stories
Themes	B1. Doing the right thing right	B2. Reflecting on mortal time: nurses' stories of personal & professional vulnerability & maturation
Categories	B1.1 Doing the right thing right: Respecting choices, beneficence and distributive justice, valuing dignity and personhood, truthtelling, advocacy B1.2 Creating and shaping solutions B1.3 Differentiating roles	B2.1. Reflecting on the experience of mortal time B2.2. Reflexivity: Developing expertise and challenging assumptions B2.3. Acknowledging moral distress and accumulative grief, and seeking balance B2.4. Creating spaces for new stories

Figure 11. *Sharing mortal time: Dimensions of nurses' work in transitional cancer care*

Part A: The narrative framework

Theme A1. Hearing story. *Presencing and respecting personhood*

The first theme is *"presencing and respecting personhood,"* in the psychological space that McQuellon and Cowan (2000) refer to as "mortal time." The theme represents this study's understanding of the focus on *listening* and *hearing* the stories of patients as they enter into care interactions with nurses, as the prologue to an unfolding story. Nurses with expertise in transitional cancer care recognize that ILWPC have first-hand, expert knowledge of their own feelings and understanding of their life story. This theme reflects that underlying respect for the value of attending to the telling of personal narratives as the nurse, with patient, creates the foundation of a therapeutic relationship characterized by the recognition that ILWPC want and need to feel that they matter as unique persons.

A1.1. *Listening and hearing*

From the outset of the interviewing, it was evident that the activity of being "listening ears" for ILWPC is integral to the work of nurses. The role is described in this way: "we're ears for people because they come from clinic and they've been told a certain thing and they need to talk"(K84). Katie's reference to "a certain thing" might mean the news of new recurrence of the cancer, or further spread of known metastases, along with a lack of response to a treatment regimen. Such news translates into option(s) for a change in treatment plan; but, at a deeper level, it represents the need to acknowledge that treatment to date has failed to stay the illness progression and existential issues may threaten to overwhelm some individuals. It is for these deeper meanings, not merely the words, that nurses are actively and sensitively listening and hearing. Rachel noted: "they're probably in a state of shock. So we're trying to give them a little time to come around; but, if they're needing to verbalize and wanting to talk I've always been quite prepared to go that route with them" (FG2R382). Her comment shows insight into the chaotic time of emotion and angst experienced by so many ILWPC, reactions described in Chapter Two and the model arising from this study (Appendix B). As will be further discussed in Theme B2., the nurse too reflects on, and is affected by, the impact of being there and hearing the story of that "bad news":

> Women will come to the treatment room having received news and...I always sit down with them first before I do anything and see how they're doing and things like that. And they will come *right* out and say, 'well, I've recurred,' or the 'CT scan showed this,' and 'it's not working.' Right there on the surface....I can't even imagine being hit with that news. Like I…I try and put myself in their shoes and it's just so hard to even imagine… (K453).

The idea of being there as a sounding board occurs in a variety of circumstances. It may be in direct relation to the patient (e.g., "you're just there to kind of...help them express themselves"(K289)), or to family members (e.g., "she needed to talk, and so we would spend time with her and, you know, allow her to cry, and allow her to express what was on her mind" (K363-367)). Nurses illustrate how important they feel "being there" is in the role of nursing, in that the acts of sitting down, listening, and being present add to the dimension of trust in the relationship (M1136; Kr221-224; Sp365-375). As maturity in nursing evolves, presencing becomes not only a more comfortable activity, but one which is prioritized (FG2S290-91; K388). Perhaps such reflections are a mark of the expertise described in Chapter Two, and which framed the peer-nomination process in the study recruitment of participants highlights (Appendices E and F).

> When I was a younger nurse—in a sense of less experience—I always used to think that I had to *do* (emphasis), do, and *do*, because that's what nurses did… that is, they *do*. (emphasis) (laughs) I remember learning that you know, sometimes nurses just have to *be* (emphasis). And they just have to *be...there.*

> That sounds kind of cryptic, but I think you know what I mean. It's a very important role (K564).

The second focus group was held during national recognition of "Nurses' Week." One participant who had recently assumed management responsibilities, and who expressed missing some of the dimensions of direct care, shared reflections on a chance meeting with a patient on the way to the group interview. In keeping with other nurses' experiences, the encounter underscored her belief in the importance of presencing:

> The time that I was with her she was very sick. She had two young children, she was facing life and death issues and I was there with her. You know, that relationship really started when she reached out to me in that way and I was there to help her through that" (FG2S31).

A1.2. *Weeping with*

Jenna talked in her interview in a reflexive manner about a time when she had not wanted to "go there"—that is, enter mortal time or transitioning conversation with a particular patient—because "the patient and I had just recently shared tears and we couldn't do anything but have a tear and no talking. And she was okay with that" (J 711). The discussion continued with the nurse remarking that she feared the day when "somebody isn't comfortable with sharing a tear" (J714). Further exploration highlighted her perception of commonly held professional views that nurses will be patients' strength, their support. There was question about whether or not seeing the nurse in tears might contribute to loss of hope or confidence in the nurse. In asking how she had experienced the effect of such shared tears on her own nurse-patient relationships, she thoughtfully indicated she felt such expression might actually have enhanced "a better connectedness, a genuine empathy" (J746).

This professional caution about tearfulness during the process of work was evident elsewhere in the data. Dawn stated:

> When I go and talk with nurses…there are some nurses who say 'I just fall apart every time I go in to talk to people about this'….There are some people [nurses] who have a really difficult time talking about palliative care because they are so emotionally involved with that patient, it becomes very difficult not to sit there and weep. I mean sometimes I cry, too,…at least they know you care. Just as long as you're still *effective* in what you're doing (D1038).

Such cautionary tenor comes from awareness of many nurses' experience in coping with the transition experiences of ILWPC. Nurses expressed sentiments of the profundity of constant exposure to transitional care.

> I suppose a lot of these things make me feel really, really sad. …I'm very close to the people I care for...so I cry a lot. I probably cry every day…I cry with patients all the time…I hug patients…it's just very intense. As oncology nurses we're probably sharing the most scary, intense time of somebody's life (Kr722; Kr753).

Each nurse in outpatient cancer care may be exposed to numerous situations of interaction with ILWPC in a day, hundreds of patients over a brief period, and an ever-present knowledge that close to fifty per cent of individuals receiving care may expect to experience recurrence and illness progressing to death. If one looks at the transition model (Appendix L) and multiplies the experience depicted there to represent numerous patient-nurse relationships that are being lived with in the field, one begins to have some deeper awareness of the complexity of the experience of transitional cancer nursing (Appendix M). When the intensity of that constant living with multiple situations of mortal time pervades consciousness, it is little wonder that sadness is felt, and tears are shed. Must they always be shed in privacy, or is "weeping with" a part of the work of transitional cancer care that must be accepted, responded to, and normalized? These are questions nurses—from novices to experts—grapple with daily. Further findings of this dimension of the work, and the consequences to self-care, mentoring, and broader institutional and policy-related responsibilities are explored as connected categories in Theme B2. and the discussion in Chapter Five.

The importance of respecting the patient's lead in the matter is another attribute of *"weeping with"* and is noted in the focus group discussion: "if it's a moment of extreme emotion and crying, we'll just sit quietly or explore the tears at that moment... I kind of always let them take the lead" (FG2R603). Such respect for the patient's leading reinforces the idea of enabling storying through empathic, responsive hearing. It also contributes to the establishment of trust, a critical consequence of *"weeping with"* that doubles as an antecedent to the next category, that of *"connecting with,"* as well as to the supporting of storying and preparing ILWPC and their families that will be discussed in Theme A3.

A1.3. Connecting with

As Jenna noted (J746) the tears that she shared with a patient led to a feeling of greater connectedness and genuine empathy. Listening and hearing and shared tears evidence approachability and openness in the nurse, characteristic traits of engagement of the nurse with persons in a manner that reflects a certain trustworthiness. In the state of vulnerability that so often accompanies transition, ILWPC seek ongoing opportunities to spend time with a nurse where that sort of trust has been previously invited and engendered. The importance of presencing as characterized by connectedness is reflected in the description of how ILWPC sometimes "gathered in their circle" of "chosen" care providers in the treatment area where there is a system of "first come, first served" allocation of treatment nurses to accomplish the necessary work (K1046). Nurses too seek out those opportunities to connect and be there for certain individuals because they already know some of their story and want to maintain care continuity and build relationship in order to respect the needs of patients for ongoing relationships with their care providers. The treatment nurses in the study confirmed a certain envy of the clinic nurse role where there could be greater protection and use of "actually really connecting with them" (K1112). This privilege was confirmed by comments from those who enjoyed that part of their role (e.g., FG2S18, FG2S467, FG2S1097; FG2J228; M352; FG1M704; D286) or observed that engagement with patients in others (FG1Sp744). In fact there was lengthy discussion in the first focus group (FG1M-Sp660-872)—sometimes with protective sensitivity—about care continuity and how that was influenced by nurse-patient relationships, and also how valuing connectedness and presencing was facilitated through team efforts. Along with the cohesiveness of team, however, times of tension were also acknowledged. Connectedness with some members of the team precluded patients' sharing of information in a consistent manner with other members, resulting in some decisional confusion as seen in the following excerpt:

> She was slowly declining and still wanted aggressive treatment… The treatment nurses tried to maintain continuity, so one nurse did look after her as often as she could. She [the treatment nurse] came to us and said, 'she's telling me she just can't do it anymore.' And so as a team …we went and talked with her to revisit where we're at 'cause she's told *us* [the clinic nurses and physician] she wants aggressive treatment… It didn't work that well because she was still waffling back and forth... it was clearly an indication that she was, I think, transitioning into perhaps a different approach to her life than what we were doing. It was pretty awful…(FG1M 813).

Perhaps this confusion, or "waffling back and forth" (FG1M 830) is symptomatic of the angst generally felt in the uncertainty and vulnerability of transition experiences (Appendix B), and may explain in part the need for people to feel connected to at least some care providers in an anchoring and trusting relationship. Too, this scenario underscores the need for team function and awareness that ILWPC may share different perspectives of their illness experience and story with different members of the team, and that the consequence of connecting is a critical antecedent to *"doing the right thing right"* (Theme B1) in *"differentiating roles"* (B1.3).

The phenomenon of multiple reactions to transition lends further credence to the nurses' belief in the importance of understanding and respecting persons as will be discussed in the next category, *"respecting personhood."* But just prior to that, it must be acknowledged that "connecting" is not exclusively within the purview of nurses who are privileged to have *ongoing* relationship with patients. Vanessa noted that though she often works in a consultative role, there is significant meaning for both herself and some individuals in mortal time encounters of limited duration. In the focus group she shared this memory of assisting with the transition to palliative care and how grateful the family had been because she had made all the arrangements that made a significant difference to their experience. She recalled:

> Interestingly enough, when she died they didn't phone the nurse and the physician [they had been working with over time]; they phoned me, and thanked me. I only had that one encounter with that patient. (Participant S Wow!) It's kind of amazing, but I felt during that conversation that somehow there was a connection that developed there, you know? (FG2V1200)

A1.4. *Respecting personhood*

Respect for the personhood of patients while responding to them was pervasive in the manner of the respondent-informant nurses. Preparation in anticipation of difficult situations, along with follow-up to them, was identified as routine practice (e.g., M343, D1002, J678), and frequent use of phone calls, even occasional home visits, extends the outpatient clinic service as appropriate. In the view of these nurse participants, there was confirmation of a belief that the professional tradition of nursing regards interactions with individuals in a holistic way. Such holism was contrasted with the medical biological model that nurses frequently observed in care provision. (That professional contrast and interface between nurses and physicians is explored in Theme B1 in the category of *differentiating role.*) The category, *"respecting personhood,"* reflects an enhancement of providing and then supporting choices of ILWPC by getting to know their unique situations, and of encouraging dignity by seeing them as whole persons with much more than tumor activity influencing their care. The importance of spending time to understand and learn more about the individual is reflected in these comments by Mary:

> [Having the discussion] gives you the opportunity to understand your patient's special needs…I'm thinking about a patient who is a Jehovah's Witness…we had huge discussions up front. It gave the whole team, and her, and her family the opportunity to all understand what her wishes were now and what they would be…and it made us feel more comfortable, too, in knowing that we could help her to go down the path that she wanted to go… Even though we might not understand it or agree with it, we wanted to go down her path (M343).

Thus, respecting personhood was explained in terms of holistic approaches and connecting information that comes from hearing the individual's story (D876; D1167). Nurses cited patient tendencies to comply with second, third, and fourth-line treatments suggested by physicians, simply because patients really did not feel they had a say in their care (K570; D1145; E 649; FG2R395), or because patients had misunderstood the intent of what the doctor had said (FG2S298; FG2S363). Katie informed this aspect of differing professional perspectives in presencing this way:

> I have found that doctors are extremely tumor focused. I'm not saying that that's a bad thing, but nurses look at the whole person, and sometimes doctors kind of forget that. People are *multi-dimensional*, and you can't forget that people ...um... aren't just a tumor. It's a very *detached* way of doing things, and, maybe they need to do it that way… I don't know. There's been an exceptional doctor here

> and there who *has* been *extremely* holistic in his or her care; but, *I've* just found it's important when you can sit down and listen to where a patient's at. I used to go out there and say all kinds of things 'cause I felt like I had to *do*, but now it's more ...I listen and then I say (K582).

A1.5. *Being with, while doing for*

In keeping with respecting the wholeness of personhood, findings reflect congruency among the participants in valuing the professional desire to combine treatment of the physical needs with the informational, psychosocial and spiritual needs of persons in transitional cancer care. If nurses in the nurse-managed clinic feel that patients may require lengthier time, appointments are adjusted accordingly to facilitate not just the clinically focused care and treatment, but to provide response to other issues as well (E781). Some differences in control over contextual factors existed between the clinic settings and treatment areas. Though there are recognized challenges in maintaining privacy in the treatment rooms, where there is little to facilitate an "intimate setting" (K687), "being with, while doing for" was still an aspiration: "if I can just really *focus* in on them and sit as close to them as I possibly can. I mean even if it's a brief conversation of five or ten minutes, if you're sitting there pushing a drug, there's lots you can talk about"(K692). Professional peer respect for the action of "being with while doing for" was noted (e.g., "we usually let each other know we're going to talk to so and so, and 'I'm gonna be a while'...and that's respected"(E411)). For some of the nurses, the benefits of recent environmental changes—a new building—that facilitated greater privacy and fewer interruptions (D756; E411; FG2S338) was identified in support of the idea that environmental influences are antecedents to effectively combining presencing and significant personal discourse with activity that is treatment focused. Situations still hampered by some of these barriers to presencing are correlated with both Theme B1 *("doing the right thing right"),* and the next theme of *"discerning readiness,"* a critical process in which sensitivity to the interpretation of the stories being shared by patients with nurses is paramount.

Theme A2. Interpreting story. *Discerning readiness and broaching issues of mortal time*

Having good judgment or insight, a description of the meaning of discerning, is associated with the ability to perceive clearly with the mind or senses, to make things out by thought, gazing, listening and other processes of information seeking and sorting things out (Canadian Oxford Dictionary, 1998). As has been described in Theme A1, listening is an essential antecedent to the process of discernment. That is, nurses work to determine whether or not the patient who is in a clinically determined state of transition away from curative possibilities is also "there" emotionally. Numerous factors influence the stories of ILWPC, and nurses are called upon to discern the salient—as well as subtle—influences that affect the experience of transition into some level of awareness of one's mortality, particularly in relation to the presence of serious and advancing cancer. The hoped-for consequences of sensitive and timely discernment are that the individual who is understood to be facing death within weeks to months may experience a period of transition and mortal time that is as healthy as possible, in alignment with personal goals or wishes, and their personal indicators of quality of life (see quality of life notation in key terms section of Chapter One); and, that there is the desired support provided by others who are a part of the individual's storying during that time. For the nurse, satisfying transition is described as "making a difference," or helping "them to take one more step down the road, even though you know it's difficult for them" (E728). Such positive outcomes are not always realized; nor may they even be acknowledged or desired by ILWPC. The multifaceted processes of discernment challenge nurses daily, and the study findings reveal a spectrum of opinions and practices related to this core theme. The focus groups confirmed disparities, questions, and tensions which individual interviewees had described regarding issues of readiness, timing, contextual factors, and the use of particular language in the discourses surrounding illness progression. The categories that follow emerged from the data, and have been identified as critical dimensions of nursing discernment. Recognition of *process* as salient to transition is a thread throughout the findings; but it is an especially significant dimension that frames each category within the theme of discernment.

A2.1. Grasping the situation

Dawn, a nurse often called upon to broach palliative care in response to a referral, described how she made an initial assessment of the room, the people in it, and any signs of distress, receptivity, or other more overt emotional expressions ("I do a little assessment of the room. Who is in the room, is the patient alone...? I look at the faces of the people...do they appear upset? ...Often I will say... 'I understand you've had some bad news today'...and usually that starts them talking..."(D110)). Acknowledgement of the events or information leading to the referral and ferreting out patient and family understanding of the situation also seemed to contribute to her perceiving such factors as the urgency of the circumstances, and her discovering what the ILWPC and his or her attending family members might understand about the concept or available resources of palliative care (D120). Astute clinical knowledge (e.g., signs of illness progression such as profound fatigue together with declining ability to cope with activities of daily living, treatments, and relationships) was a significant factor that the participating nurses identified as antecedent to correctly assessing cues of readiness (e.g., E114; D103; M341; J122). Clarifying the patient's desire to know certain information is something else that expert nurses integrate into their practice, having learned that some people do not *want* to know (D126; E94; J580; M333). In the context of discussion about readiness cues in the second focus group, Sarah noted that there is a spectrum of information-seeking behaviour representing the uniqueness of individuals, and that "it's been a challenge as a nurse to feel out where they are along that spectrum" (FG2S635).

Having a grasp of the situation is important to the patient as well as to the nurse. Indeed, part of the way *nurses* "grasp the situation" is by assessing whether *patients* have also "grasped the situation." Jenna related a story of a family situation where there had been family history of a "horrible death" as follows: "and the gentleman said: 'So this means the end. As soon as you're on morphine you know this means the end.' So to work through those myths, issues and concerns has taken a lot. But I think by the end of last week they had a better grasp of their situation and a little more acceptance" (J560). The story of a woman who *had* grasped her situation and taken action before she became too unwell to do so is cited by Spencer. "She knew. She had a long time to deal with her illness and she knew this was it" (Sp557). Spencer further explains that though this teacher had lived with her partner for over 20 years, she had decided just before there was clinical evidence of more severe progression of her disease, that she wanted to get married and did so. "That was important to her, and you know, she wanted to tell about that" (Sp590). Also when there was the antecedent of no longer coping with the demands of the illness, this particular individual received the supports of palliative care willingly. This sort of readiness behaviour is associated with "taking care of business"—relational, spiritual, financial and personal—a settling of affairs that was described as a task of transition that was not unusual. In the context of Spencer's story-telling, the nurse was noting the patient's readiness to transition to end-of-life—as opposed to merely perceiving more advancement of her disease as a chronic care situation—because of this patient's personal insight, a knowing of self, and a responsiveness to the timing of the nurse's suggestions about palliation and supportive care. It is also of interest to reflect on the nurse's perceptiveness embedded in her use of words, "She wanted to tell about that"; that is, in reference to the woman's marriage after living in a common-law relationship for years. This part of the story also fits with Theme B2's narrative framework of "creating spaces for new stories."

A2.2. Reading readiness cues and "feeling your way"

There are dilemmas, however, for both nurse and patient in grasping the bigger picture. Nurses feel significant tension about whether or not discussions about end-of-life should be *routinely* incorporated into early teaching and presentation of treatment options for all individuals living with the knowledge of advancing cancer, regardless of an assessment of the patient's personal readiness for coping with discussion of these matters. The participant nurses discern that there *are* circumstances—such as in the case of individuals facing stem cell or bone marrow transplant, an aggressive therapy that carries high risks for potential, often rapid, death from treatment complications—in which the approach is routine initiation of discussion up front. Discussions include information about advance health care directives, consideration of settling personal affairs and relational concerns, and the encouragement to share personal wishes with social family members and other primary care providers, so that in the event of unsuccessful treatment outcomes proxy decision makers for the patient will be able to intervene with a sense of having a grasp of the situation. Nurses in the outpatient clinical area caring for individuals undergoing bone marrow transplant include this information in their patient education "right from the beginning" (Kr 127). The discussion related to "mortality and dying" (Kr142), however, is also couched in the primary focus of care, reiterated by Kristen several times as "we are geared to trying to save their lives"(Kr126). Mary stated this:

> We do bring it up at the very beginning because transplant is such a risky procedure. We talk right up front that there is a chance that you will die from complications... We encourage all our patients to have proxies (who would you like to make your treatment decisions, M391), and...that's still in the hopeful phase, you know? And, so we do that all along and we bring it up at important times, again. You know, 'did you need to discuss what will happen if things don't go the way we hope they will?' Or, 'if the disease comes back, what would you like to do about it?' I think in that way we may be a little luckier than...than some other clinics where you just *don't* really talk about it as much (upward inflection.). But in saying that I can think of one young man, who...who went through an awful lot and we did talk about it all the way along, but he said 'I'm not listening.' He may not have used those words, but it was clear he wasn't listening when we said, you know, 'you may die from this procedure.' You could *see* him tune you out (M384).

This was a significant story in pointing out the dilemmas of understanding the bigger picture for ILWPC, because Mary illustrates that even when there is factual information shared about end-of-life care issues early in the processes of care and treatment decision making, people still have their own sense of timing and readiness to "hear" and "accept" information and guidance related to mortal time. In the individual interviews as well as both focus groups this tension about timing was linked with a concern or fear of taking away the hopefulness of patients if mention of death and preparation for that eventuality is initiated. For instance, Vanessa noted that in one situation a teen's disease progressed quickly and she recalled the following with some regret: "unfortunately…I don't think that person *ever* got the discussion…they [the family] felt it would cause emotional distress and she would lose hope" (FG2V905). Sarah responded with her own story from which the following excerpt is taken: "They [parents of the ILWPC] didn't want the last six weeks of his life to be one where he would be depressed, or lose hope, or whatever…" (FG2S989). Conversely, a similar reason was given by a physician who had explained to Sarah that his lack of forthrightness in explaining a grave prognosis "was so he wouldn't take away the hope" (FG2S307). In sharing a story of one young woman facing bone marrow transplant, Mary indicated that in the face of uncertainty about the outcomes of such life-threatening interventions, "it is harder…because we don't want to take away all the hope, yet we need to get them the support they need…Her mother needed to be prepared for the possibility of her dying at home" (M177).

The first focus group had a lively discussion about the tensions in this area. Mary spoke of her view that up front discussion was putting conversation about wills and advance health care directives "into the context of being prepared for all eventualities" and "we all need to be somewhat prepared" (FG1M274). She shared that she had used the same approach with someone close to her who was newly diagnosed and living with breast cancer. Though this relative had been annoyed with Mary at first, she later thanked Mary for helping her to get in order things that she had not done before, saying: "I hope you do that [getting preparations done up front] with all your patients" (FG1M311). In responding to Mary's comments, Spencer, a nurse with less regular exposure to direct discussion with ILWPC, admitted her discomfort with such an approach: "certainly for a woman who is metastatic, or moving on, yes....but for someone newly diagnosed...I would not want to go there" (FG1Sp294). Spencer went on to wonder "whether it's the nurse's role to say to a newly diagnosed patient 'make sure your affairs are in order'"(FG1Sp321). Though Mary admitted she felt it was harder to broach if you "haven't established a relationship yet"(FG1M 315), she also felt that it became easier if the topic was normalized: "we talk about it as though it is something that's just part of the planning" (FG1M330). This latest comment was then further contextualized by her saying how important she felt it was to understand the special needs of the person, and what *their* wishes were (FG1M343). Though Spencer at times deferred to the greater clinical experience of Mary, the discourse reflected the concerns and supportive views of the individual interviewee participants as well as the second focus group, too. The core dilemma has to do with the respect for person, appropriate timing and nursing agency.

Indeed, in the field of cancer care nursing, it is common to hear nurses and other team members talk about whether or not individuals with advancing cancer are "ready" to enter into discussions related to mortal time awareness. Antecedents to readiness in ILWPC were associated with declining functional status or physical deterioration, serious clinical evidence of disease progression, lack of response to treatment interventions (e.g., chemotherapy and/or radiation therapy), circumstances in which persons could no longer tolerate any treatment options still available to try, or illness for which there was no available treatment other than palliative relief of symptoms (e.g., K452, K789; D165, D207). Avoidance of treatment appointments or the expression of direct questions about hopes for the future were also described as signs of possible readiness. Other terms that nurses used that described traits related to readiness behaviours included openness, preparedness, and receptivity (e.g. "so you broach it at a time that you think they would be receptive to it," E65). Some nurses indicated that they initiated the conversations with patients upon direction or referral from physicians (D103), often directly linked with the medical indicators of disease progression. Other nurses stated they were the ones to broach the discussion relating to palliative care referrals first, and that in their area it was rarely the physician who presented palliative care as an option for the patient to consider (E61; FG2S423; FG2V551). In both situations, however, there was communication between these members of the health care team about the patient's circumstances and needs.

The following textual excerpts also point out that some persons are not ready: "You can try and broach it, and ease your way into it, and they are *clearly* not ready, in that they just want... 'just keep doing whatever you can do to keep me alive.' They're clearly *not* ready for this discussion, no matter how gently you try and broach it with them; or, they're not receptive to it" (E94). Dawn spoke of being met with a lot of anger when going to speak with some individuals about palliative care and how a number of issues could interfere with their readiness:

- *blame* ("you [the health care providers] didn't do the right thing," "the family physician didn't pick this up soon enough," (D612, 618))
- *dashed hope* in the context of having had hope in treatment changed by the words of the physician that the treatment has not made any difference (D610);

and,

- *disbelief* and *uncertainty*.

The following passage sheds further light on Dawn's reflections about the issue:

> Sometimes you have to deal with 'I'm feeling okay so I can't have…' [things like pancreatic cancer]. They can't wrap their thoughts around it—'they must have made a mistake.' It's hard for them to believe they have a terminal illness; so if they're not, I guess, *accepting* of the diagnosis then it becomes very difficult to talk to them about palliative care. It's also been difficult to talk about palliative care when the *family* isn't accepting of what is going on. They still want to be aggressive and they're searching for alternative therapies (I guess we call it 'treatment-seeking' behaviours), so in that respect I will back off the palliative care issue because nobody is *ready* to talk at this point. They're still looking for treatment, so the focus is not on quality of life, it's on curing the cancer (D604).

As can be noted above, another unsettling situation relates to asynchrony of readiness between some ILWPC and their family members (D634; D1087; E339; J89; FG2S638). Emma described how difficult it was to work with a family who wanted to protect their mother from the knowledge of further metastases, and in both focus groups there was discussion over similar issues. There was animated and empathetic discussion in the second focus group when Vanessa and Sarah shared poignant stories (see Theme B1, category B1.1.4, *truthtelling*) of situations where parents of older adolescents wanted to withhold information, yet the involved health providers perceived that these teens with rapidly progressing terminal illness were insightful about their own remaining life (FG2V875; FG2S940). Trying to balance the perspective of the parents with what they discerned about the teens' readiness, led the nurses to distress over whose needs and wishes would/should be pre-empted. The experience of such tensions often resolved over time, as many of their stories validated (e.g., Theme B1, FG2J758; FG2V875; FG2S940).

Timing for broaching issues of mortal time was seen to be integral to nursing agency. The process of ascertaining preferences of ILWPC and how, when, and what information they and their families want shared with them requires wisdom, tact and tremendous discernment. Emma described the process this way:

> Let's say you were the patient and …clearly your treatment wasn't going well and we weren't achieving, say a remission of your tumor size no matter all the things that we've done. ...I would bring *that* up gently and say, it doesn't look like we're getting where we want to go. Or, if their body is really *physically* starting to wear down then I would say, you know, even though your *spirit* seems very strong, your *body* is saying it's tired because of…[these examples]. And the patient will *agree* with those things, and, by their *body* language, or by things that they'll say such as, well what can I do now, or where do I go from here, then we can carry on with the conversation. But a lot of times it's *body language*. ...you know they're not sitting ramrod straight, and kind of, looking away from you. They're looking at you and they're *encouraging* the conversation (upward inflection.) (E114) … You're *feeling* your way along a lot of the ways, but you're watching for all of those cues—the visual, the words, the *tone* of voice even—you know? It...it's not sounding angry and harsh. It may sound very, *very* sad, but, it's ah, it's *open* (E141).

Katie recalled having to respond tentatively to a patient who was in shock after hearing from a physician the bad news about her progression of illness. "She didn't ask any questions of him, she was just laying there in shock like she wasn't hearing him. So I had to re-explain things in a clear way, but in a gentle way. She wasn't ready to hear it" (K202). Interestingly, nurses also used the terms "gently" (K175), or "feeling your way" (FG2J724), or "not pushing people too hard, introducing small steps" (FG2S1614) when describing *how* they raised the issues salient to transitional care. Discussion in the focus group between Rachel ("Do you always respond to the patient or family's comments? Is that your open door?", FG2R541) and Vanessa ("sometimes I initiate it that way," FG2V538) was interesting as they explored together and then with others, whether this "raising of the issues" was done in response to specific cues provided by the patient and/or family, or if there were times when timing was more proactive on the part of the nurse. This core issue was reflected universally in the individual interviews as well as the focus groups. The concern had to do with wondering if there was need to "wait for permission," a question raised by Rachel in the context of discussion about the nurse-physician dyad with the patient (who does—or should—initiate such conversations?), and how the seeking of congruence in care goal setting needed to be the shared outcome. Vanessa interjected her story of a recent experience of needing to *initiate* dialogue—*not wait* for an opening—with a woman in her seventies who had been in the Intensive Care Unit and successfully resuscitated after a number of cardio-respiratory incidents. As the palliative care nurse clinician she had been asked to see the patient, and while Vanessa admitted to surprise at the woman's answer that she *did* want aggressive treatment, she described how important it had been to the team to discern what the patient's goals actually were (FG2V551). Awareness of this matter was achieved only because they (i.e., a speech therapist and the nurses) had chosen to take initiative and clarify the patient's understanding and wishes.

In addition to what patients and their families may actually say, their body language, voice tonality, body posture, and expressions in their eyes convey significant cues (D1084; E114,141; J122; J580; K197; M412). These cues may present in the form of the following examples of observed behaviours:

- engagement, an invitation to continue ("when they look at you there's something in their eyes saying, 'I know what's going on. Be honest with me.'" (J129))
- dismissal; disengagement ("you could see him tune out" (M412))
- withdrawal ("it's like she... put this *wall* around her 'cause she just didn't

want to hear. ...It was a physical manifestation, it was just very obvious that she um, sheltered herself from it. Some people cry ... she didn't cry. And that's fine, that's the way she dealt with it. She withdrew. She really withdrew." (K217))

- anger ("if they're sitting there with arms crossed, you know, looking kind of angry, that usually tells me, maybe this isn't the time." (D1087))
- determination ("'We have to keep trying, I'm not going to die.' There was no way she was going to quit. We had come up with this great plan to support her—her quality of life, palliative treatment—and she was having none of that. She listened politely, then made it clear she wasn't participating. She was actually quite delightful!" (M290)).

The nurses also commented on ways in which they discerned readiness cues or struggles with acceptance on the part of families of ILWPC. Understanding and acceptance were identified as consequences of readiness, whereas anger, distrust, disappointment, and pressure to seek further treatment options were behaviours of the "family that is struggling" (J587). Dawn also noted that less blatant cues are picked up on as a result of an "intuitive sense," combined with "people skills," increasing knowledge, and experienced awareness of what processes people go through (D1295).

The comments and narratives used by the nurse participants reinforce a persistent thread throughout the findings in relation to behaviour that is characteristic of expert practice—characteristics that are found in Dawn's comment about intuition and knowledge reinforced by experience. The expertise of the informant–respondents guides further discussion about discerning appropriate timing for broaching transitional issues, in that they have been able to decipher what factors either affect, enhance, or challenge effective transition and readiness behaviours. These factors will be explicated under the following two categories of the theme of discernment.

A2.3. Paying attention to contextual factors

The "lenses" of age, gender, culture, race, religion, family and relational dynamics—including level of support systems, and various other special needs—were referred to by the informant nurses as they described a variety of influences that they perceive shape the readiness of patients to transition. Some of these factors also contribute to enhancement or challenge in the work of transition for the nurse-patient relationship; thus, exploration of these issues will be partly dealt with in the context here of discernment, but also in the remaining themes through discussion of the work of nurses.

A2.3.1 *Age:* While exceptions were acknowledged, a trend was voiced, both in generalities as well as in the form of individual stories, in the nurses' thinking that more advanced age was associated with greater readiness to enter mortal time.

> It depends also on the age and the family dynamics, too. The ones that I've struggled with the most are senior men who…they're widowed or don't have any family. …I probably …spend more time with [them] because they are so alone. And I think I really struggle with the younger moms or dads and the kids who have been diagnosed terminal very early on in their life. It just doesn't seem that easy to deal with for them. It's somehow easier for somebody who is eighty and they've had their life and they've got lots of, um, good memories…and [a sense of] life completion…if that can be used. So those discussions somehow flow a little bit easier and the words are easier to find than [for] someone who's so alone, [or] so young.(J311)

In several different contexts, others also commented on age. Katie observed that elderly individuals sometimes offered reassurance to the nurse in terms of use of phrases such as

"I can handle this," or "Don't worry about me, dear" (K374). While noting the exception of a few elderly persons who sought and tolerated treatment well even in their 90s, Katie also observed that "very few older people—I'll say seventy or over—have *fought* the palliative process. I'm not saying they *like* it, or that they're not struggling with it to some degree...but, I'm constantly hearing older people say, 'I've had a great life'"(K838). Katie also described how many of these persons seemed to be able to reframe their hope in setting reasonable goals, seeking quality of life, while still living within mortal time awareness (K300). Dawn commented on the ability to cope with transition as being influenced by where individuals were in their life cycle, contrasting greater ease with transition when "the elderly know this is part of their life journey…they have had a long life and they know this is part of the aging process, this journey to death"; whereas, "if they have young family, the transition is much more difficult for those individuals because there's a lot of issues around who's going to raise my children, what will happen to them" (D 468).

Another dimension of patient age on the health care professionals who are transitioning alongside ILWPC was reflected in Mary's comments. She recounted a conversation earlier that day in which "a palliative care physician was saying how difficult it is to work with our patients [those receiving bone marrow transplant] because it's 'so emotional—they're all so very young.' That's not true, but many *are* young" (M93). Katie echoed similar personal impact in her comment on a story of a young woman in her thirties who was transitioning with advanced cervical cancer: "It was hard for me, too, because I was dealing with someone my age" (K254).

A2.3.2 *Gender:* In response to the question about factors which influenced transition readiness, there was some disparity about the significance of gender. It was raised as a consideration by some interviewees, but when broached with the participants in the focus groups there was less consensus. Some nurses felt there was no general difference in openness or receptivity to transition to a focus on palliation in the setting of care goals; others felt there *was* a trend that was notable, often associated with social perceptions about general openness in communication styles and societal expectations about gender roles and behaviour. Jenna's opening line in the citation related to age (A2.3.1, J311) reflects her observations about elderly men who are alone. Katie noted her opinion in another example:

> Women seem to be so much more, um, *open*, generally open about their feelings and the grief around realizing that they're not going to be around to see their daughters grow up or their sons grow up. Men grieve, absolutely they do, [but] um, out of all the young men that I've looked after—say in their twenties or thirties, even in their forties, but certainly those with young children or young wives—they *don't* tend to be as outwardly expressive... They *don't* even sometimes like to talk about things. Recently I was treating a young man—he has since died—and he had two little kids at home, he was always extremely polite and, talked about everything else *except*... It was very hard to see where he was at with things. Men have this incredible feeling of responsibility as sort of being the provider and things like that, and a lot of their concern revolves around how their wives are going to cope with children after they die. But I find that they are more of a *challenge* in a sense, because they don't come out very easily and talk. So you have to really draw them out. Maybe ... they didn't want to seem weak, or um...they wanted to remain strong for their wives. I'm not sure... I remember one young guy and his wife...that was terrible, they just sat in the room for days before he died and said *nothing*. Nothing. And then his mother came from overseas and within two days he died but... *nothing* [*said with mixed puzzlement and sadness in her facial expression*] (K 328).

Katie went on to contrast her general perception with the following story:

> He was in his thirties, and his wife had given birth to their second child two days before he died. She brought the baby in, he held her and he was *very* verbal about how he was feeling... but he was one of the rare ones. (K402).

Katie's observations uncover potential assumptions—perhaps a social construction of gender response to illness—that may influence responses of some nurses to the communication patterns of ILWPC. Silence itself may be speaking volumes to us as care providers, and this observation will be further discussed in Chapter Five.

Spencer responded by noting her perception of trends in behaviour in younger women with breast cancer, describing them collectively as "real go-getters" (S234) and that "even with metastatic disease they're planning" (S235). She recalled one woman with advanced breast cancer who was planning for her daughter's Bat Mitzvah which "wasn't going to happen for three years, but she was already making the lists and doing things because she didn't know if she was going to be there" (S242).

A2.3.3 *Religious faith and culture*: This story also elucidates the role of religious and cultural matters in the nurses' discernment process. Spencer went on to comment on the strength and determination of this woman, and how her seeking of further treatment happened in spite of (or because of) her openness and awareness of her limited time to live. Dawn, too, noted the need for cultural awareness and cultural-societal influence on language (see more discussion in category A2.5) in this comment:

> You have to be culturally sensitive too. I think there are some cultures where talking about death is not accepted, so you have to be aware of that as well. You may not talk about them dying, per se, but you can still talk about giving them a good quality of life—looking after their symptoms and those types of things—without using those 'dreaded' words of *palliative* and *terminal* (D733).

Other nurses noted religious faith as a context for influencing readiness behaviours. In describing a man who was receiving aggressive treatment, Mary said:

> This is what he wanted to do. [Earlier] he had said: 'You know, I have things to live for. I have a good life and I want to be able to live.' And I remember going into the exam room with the physician, and we were telling him [the patient] it was getting worse. We put the CT scans up to show him—'cause this was a fellow who liked to look at his [films], you know, he adjusted better with that—

> and he looked at it and said, 'Oh… Well…I guess then I'm going to die, and that is all right, too.' And I thought, [*reflection of both surprise and almost nervous laughter, humour at self, in informant's body language and voice tonality*] I've never seen anybody adjust quite like that! ...And it's not just that he said those words [*said more quietly, reflectively, respectfully*]. He...he really, um, seemed to believe them, and right till his death did—that this is okay—you know? He had a strong faith (M257).

Jenna, too, related a story of having to grapple with a patient's seeming outright acceptance of his disease progression and subsequent refusal of palliative radiation therapy—treatment that is commonly used in situations of spinal metastases where spinal cord compression may be averted, at least temporarily, by intervention. In seeing into the heart of his apparent ease with entering mortal time, Jenna provided enlightenment with the following: "borrowing some of his words, he was a very Christian man and had come to accept this was what God had in mind for him and he was complete" (J456); "he had made his mind up that he would die at home in peace" (J479). In this situation, this man's relationship with God was paramount to his decision-making and apparent ease with transition.

A2.3.4 *Social family dynamics*: Nurses discern that other relationships can also set the stage for enhanced timing and the readiness for consideration of end of life, and nurses integrate awareness of how these relationships may affect the care of ILWPC. In particular, family dynamics were identified by all the nurse participants as important in a variety of contexts, including the role of primary social and care support. Nurses perceive family relationships as sometimes helpful and sometimes a potential source of challenge to ease of transition for the ILWPC. Emma noted that family relationships play a significant role (E377), and that she thought that "a family that is close and gets along well…tends to do a little better" (E385). Jenna contrasted two examples of family readiness and receptivity to transitional care. The first excerpt illustrates her description of a family that demonstrated cues of readiness behaviour:

> The family asks questions in a calm, very directive manner. They're very information-seeking. And I can provide them with the information that they're seeking, answer the questions as they ask them, and they accept the answers. So you can tell in the tone and when, you know, you ask for their clarification, they have an understanding (J580-587).

The following is her description of another common situation, the "family that is struggling" (J587):

> You can hear the *anger* in their voices, and the disappointment with the answers that they're getting. And I know they're gonna take a lot more *work* to help. I don't know—this one particular family—if they really trust and believe that we're hearing all of their questions and concerns. We *are*, but they aren't...they aren't ready for that. They don't want to believe that right now. They're looking for *more* (J606).

In addition to the description provided by Dawn (D604) in the discussion of readiness (A2.2), Kristen also noted that if a family struggles with the notion of the ILWPC "giving up," this created challenges for the patient: "If somebody's got ,you know, 'oh you can't give up, I'm not ready to lose you,' from your spouse, well that's a bit of a barrier...How are they going to move into that sort of peaceful end?" (Kr1457). Kristen revealed empathy with the family's feelings in her comment that "sometimes *we're* not ready to lose these people either" (Kr1474), highlighting the influence of dynamics in the nurse-patient relationship on the experience of transition, including anticipatory grief.

A2.3.5. *Nurse-patient relationships*: In expressing her observations about influences on transition Emma stated that "the relationship between patients and nurses is paramount to having a good transition, if you have a close relationship, ... and that they respect the nurse's opinion and the guidance that comes with that" (E388). Mary's story of her initial disbelief that the man who looked at his CT scan film and then seemed to face the news of recurrent and significant advancement of his disease with uncommon equanimity (see earlier quote, A2.3.3, M257), was made more believable within the context of their ongoing, respectful care relationship. She spoke of continuing evidence of his truly comprehending the reality of his situation, and that his initial comment that exuded acceptance was not a reflection of shock, denial, or misunderstanding that might have been suspected in others if they were so calm in the face of receiving devastating news.

Another story that reflected the importance of relationship came from Kristen. In this exemplar she related how the parent of a young woman came to her to ask that she be the one, rather that the physician, to assist the patient in learning about palliative care because her disease was progressing ("when it was coming right down to the fact that we couldn't offer her any more treatments she wanted me there," (Kr208)). The request was due, in large part, to the strength of the nurse-patient relationship ("the relationship has been so intense over the last three years," (Kr235)), and the comprehensive knowledge that Kristen had of the patient as person. This was a dimension that the mother felt was missing in the physician–patient relationship, yet was needed given the sensitivity required in broaching issues of "mortal time" with her 24 year-old daughter.

Though all of the nurses at some juncture spoke of the importance of the *developed* nurse patient relationship in the context of influencing receptivity, several nurses presented other perceptions. Mary noted that sometimes having a "close" relationship produced a scenario that created emotional challenges for the nurse emotionally to broach sensitive topics about end of life.

> I think it's easier to talk with people if you have developed a relationship with them already. You feel more relaxed for the most part. But sometimes the opposite is true…it's just too much. …I think everybody here does a wonderful job of maintaining that professional, emotional involvement, but the need's still there. I can think of a couple of examples where the patients were pleased that it was someone they *didn't* know as well (M619).

Other participants provided descriptions of having brief but evidently significant and meaningful encounters with ILWPC. For example, Dawn spoke of the time when an initial visit led to a follow-up phone call eight months later because the person and family *then* felt ready to talk more about palliative care options (D170). She had also spoken of times when on a first and only discourse, patients and family members expressed gratitude and relief in having received the informational support and referral (e.g., " She said to me afterwards: 'You don't know how much better you have made me feel. I felt so *alone* in this. …I thought I just can't do this all by myself.'" (D963)). The association of *timeliness* in mortal time encounters versus simply the *longevity* of the nurse-patient relationship was also highlighted by Vanessa's story cited in the category *"connecting with"* (A1.3., FG2V1200).

A2.3.6 Systems or organizational influences: It was evident from the participants that systems of care had both negative and positive effects on enabling processes of discernment in the nursing role. If clinic nurses were rushed because the oncologists they happened to work for had high numbers of patients to see in a short time frame, there were implications to the nurses and patients because there was less time to attend to the personal aspects of patients' stories and the psychosocial and spiritual needs they were experiencing. Nurses in the treatment areas, as noted in Theme A1, had to work around the lack of privacy and heavy workload (e.g., “There’s not a lot of privacy in the treatment room” (K682); “We’re so busy…sometimes it feels assembly-line-like”(K1018)). Others noted that if they wanted to address these deeper mortal time issues with ILWPC, they had to zero in on topics superficially at first (e.g., “My objective is to get them thinking about [advance health care directives], ’cause in the clinic setting I don’t have the time to go through a lot of the stuff in the time I have” (D930)); or, to negotiate with their peers for more time with specific patients for whom they were anticipating such need. On the other hand, nurses in the nurse-managed clinics had the advantage of greater control over scheduling patient visits so that they could personalize the time allotment to some degree (E412). Increased numbers of specialized nursing positions having to do with palliative care referrals were also noted as a more recent benefit to facilitating transitional care. Thus staffing patterns, visit numbers, clinic management, and access to space and other supports all played an essential part in influencing nursing agency and discerning patient readiness. These factors will be explicated more fully in Theme B1.

Registration processes with the palliative care program of the local health authority was another system of organization that influenced both timing and readiness. While the young woman’s situation that Kristen referred to (Kr208, A2.3.5) was clearly related to disease progression, the nurse went on to share the story of another woman in her early twenties whose course after bone marrow transplant was less clinically straight-forward. Despite success from the treatment per se, she was living with the chronicity of life-threatening health concerns because of side effects—side effects which required intervention. Thus her situation did not always “fit the criteria” for registration with the local palliative care program which required that patients could not be receiving chemotherapy, even if therapy was palliative in its intention. The nurse participant spoke of the dilemma this way: “there’s sort of this ‘gray area’ where the palliative people are saying well you’re doing all this for her, why is she palliative?” (Kr1530). Other nurses spoke of the dilemmas that arose in taking people on and off the registration list with the regional palliative program, in accordance with the treatment regimens being provided, rather than according to where the patient was in living with the totality of their disease progression, and with their evident understanding of the goals of intervention being provided. Conversely, the nurses also made references to how there had been improvements in facilitating palliative care in their institution and that access to “supportive care” clinics was really helpful.

Dawn, too, described how she had to try to work her way around these systems issues in explaining the matter to patients, noting how some health care providers—influenced by social constructions within the system—use phrases such as “supportive care,” or “pain and symptom management,” in order to address the palliative care needs of the ILWPC without actually naming the interventions as “palliative care” (D310; 369). Herein lies an interconnection with the next category (A2.4).

A2.4. Interpreting meanings and use of language

These findings reflect some of the discussion in the focus group setting as the participants grappled with the use of language related to transitional care and how the philosophy of palliative care frequently gets subverted by the elements of more specific program criteria and the interpretation of that in clinical practice application of certain settings. This dilemma is further explored in the next category—that of use of language and the discernment that is inherent to ascribed meanings—as well as in the consequences of moral distress that nurses (and other health care providers) are then living with as a result of the confining effects of certain systems constraints (Theme B1). More about these challenges will be discussed in Chapter Five.

A number of the nurse participants spoke of language that could be alienating because of the ascribed meaning that terms or phrases had for people. The word "palliative," for example, was described as a word that provoked "mortal time" responses for many. (As noted in an earlier quote, Dawn described the word palliative as "dreaded" (D733).) In discerning this, nurses described their role of language interpretation and following up physician interactions so that clarification of understood meanings could be accomplished. Jenna used words or phrases such as "forward" ("I'm pretty forward with that and I sort of take the chance with what's going to come back at me," (J1430)), and "fairly direct and honest—maybe sometimes too abrupt" (J137) in her descriptions of approaching patients about palliation. She illustrates something that is of interest. It seemed that her communication and use of certain words was both influenced by the words of the physicians, as well as their style; yet she was in the place of having to interpret what that had meant to the patient and family:

> I think that sometimes the two doctors [I work most with] speak forward and abrupt as well, but use language that maybe isn't as always easily understandable, almost like they're talking in riddles. So that's probably why I'm more forward so that I can speak in language that the patient will understand. [I] ask them for clarification back ('Do you understand what we're saying?'), and help them to understand the terms that have been used" (J178).

Jenna went on to share her discourse with a family and patient, an individual living with metastatic prostate cancer, who had expressed their desire to seek further chemotherapy and or other treatment options:

> I said, 'You know we can do radiation, but it *is* palliative.' And they were instantly very upset with that. 'What do you mean by *palliative*? Is he going to die in six months?' So to take a step back and show them what the scans look like, and explain the progress of prostate cancer, what the cure rates are, to help them understand...how it's treated, looking at the dad's age. So they were initially not happy with the term '*palliative*'; but I had to take a step back and give them the hope that they needed to hold onto—not false hope—but to help them understand what our use of terminology means (J206).

The sentiment that hearing the word "palliative" equates to thoughts of "I'm going to die soon" was noted by others (K165; D383; S46). Spencer noted the change in a relative's perception when she explained her reference to palliative care, and the anxiety it can evoke (S39): ("'We're not ready for that *yet* are we?' And I sort of rephrased myself and I said 'No, I don't mean palliative in the true sense of the word. I mean more pain and symptom management,'...and he liked that a lot better"(S46); "'palliative' to him was 'dying,' 'no hope'"(S58)). In softening the felt reaction or perception of anxiety and fear in the patient, we may actually begin to redefine the term according to clinical application. Others pointed out that the term palliative also evokes fear, and that some individuals think that it involves no further treatment at all (e.g., D136; FG2J232). Dawn spoke of a time when she had to follow up on the anger of a patient's wife who had heard the physician refer to her husband's illness as "terminal." The term for the wife meant that her husband was imminently dying; and so the wife had "just shut her [the physician] off" (D410). When Dawn was explaining later to this wife how her husband's lung cancer was progressing, and that the physician had meant that he would likely eventually die of his disease, the wife responded to Dawn with the retort: "Well I know *that,* but he's *not terminal*!" (D386). "I had to figure out what she was talking about, and realize that we were talking about two different definitions" (D398).

The nurse's comment here is a reminder to health care providers that the impact of words on people is profound. Since it is critical to ensure that aligning—not alienating—language is used in our interactions, it is important for nurses to discern how ILWPC and their families receive and use words, and that we are vigilant about clarification of others' understanding of what has been said. In exploring the use of language in the individual interview, Spencer highlighted the need for prudence when she said: "You just have to read the person and you know what kind of language you can speak to them" (S84); "I can't honestly remember a time when people have *welcomed* the word 'palliative'" (S107). Interestingly, when asking the informant nurse how nurses could work around that perception, there was a linkage with how nurses had to interface the meaning of the philosophy of care with specific expectations of admission criteria to a program (i.e., in addition to "relief of symptoms"…"it also means no chemotherapy, no IV's, no DNR," (S118)). In contrast to this more concrete social construction of the meaning of palliation, some nurses spoke of the more encompassing—less readily measurable—sense of quality of life when introducing the concept of palliative care (e.g., "the whole focus changes to more quality of life," (K143; K188)), and of the observation that transition to acceptance of the intent of palliation may be transformative for some persons ("there's a tremendous amount of peace and …it's just amazing the physical transformation of people" (K156)).

Differences in understanding of terms were discussed in the context of both focus groups. Some participants stated they likely would *not* use the term "palliative" with patients (FG2J222; FG2S264). Others expressed a philosophical belief that palliative care "begins when the person is first diagnosed with a terminal illness" (D75); that it is "'all-encompassing,' 'not going for a cure,' but 'that it could be for a very long time of receiving palliative treatment,' and that 'my understanding of palliative care is *huge*'" (FG2R 234); that is, managing pain and other symptoms (D232, Sp49); and, "improving their quality of life" (K161; D134). Some referred to palliative care more in terms of "extra support" (E73; FG2J262), "supportive care" (Kr220, 270; FG2J230; FG2S274), or a program for individuals to access (FGJ257; FG2S271). Thus nurses recognized that if they used the term, it had to be done carefully, even cautiously, with the goal of working towards aligning, rather than alienating use of language. For instance, Vanessa stated that she tried to clarify what "part" of palliative care she is actually providing to patients when she explains her role (FG2V207). Rachel identified specifically that her "understanding of palliative or supportive is very different than what my patients' understanding is," and that "in conversations you have to be very clear on the terms we are using and what we mean" (FG2R189). Furthermore, Rachel generally followed the patient's lead in how the individual chose to refer to things (FG2R245). There seemed to be synergy around the issue of being sensitive to where the patient's understanding and feelings were. There seemed to be indication in the focus groups that the term "palliative tended to be medically-based" (FG2S266); this observation implied a decision to use alternative wording. For example, Sarah indicated "if the patient wasn't ready to discuss end-of-life issues, [the use of] 'supportive care' didn't force them into something they weren't ready to face as yet…it was a gentler way" (FG2S273).

The sentiment of all the participant nurses in Focus Group 2 was summed up by Jane, when she noted—receiving nodding heads and "m-hmms"—the theme of the nursing role in interpreting language: "we're always interpreting for the terminology that we're using" (FG2J253). Others noted that the role of interpreter was often applied to deciphering the communication of physicians with patients (K173; E647; D414), and that "we can never assume that a patient understands. You have to give them all the information that they need" (FG2S283). This last quote was Sarah's follow up of her reference to "supportive care" as a "safer term, with the provision of explanation behind what supportive meant" (FG2S280).

It was in the context of this discussion that Sarah shared a poignant exemplar of miscommunication between physician and patient, and how she as the attending nurse felt an obligation to clarify meaning for the patient. With this in mind I will use the story as a bridge to the next theme of "*preparing for mortal time*," while acknowledging that it is an exemplar rich in illustrating categories from many other themes as well, and will be referred to again in some of those contexts.

> I work with physicians that tend not to have that discussion [about transition to palliative care]. So [as a direct care nurse] it was always kind of an ethical dilemma for me...He's talking about all this treatment, but he's not saying *why* he's changing the treatment...like he would give mixed messages and he was never really forthright. (He told me it was so he wouldn't take away the hope.) This may be wrong but I felt strongly that I needed to advocate for my patients; so I would do supportive care teaching or palliative care teaching 'in the closet,' and it got me into trouble a couple of times with him. I recall specifically a patient who had an awful GI tumor. He had obstructive jaundice and we had referred him to a surgeon for a stent placement just for symptom relief. And I remember saying, 'You know he's got massive tumors. Are you going to tell him the results of the CT scan?' He [the physician] said: 'Oh, yes, I've already gone over it with him.' So I thought he would have told this fellow what exactly was in the CT report. This fellow had come in the day before his surgery, and he had some questions. (This was back when we didn't even have a private room. It was a busy clinic day, so we had the discussion in a corner of the waiting room.) He said, 'You know, I'm not exactly certain what this tube is going to do, or why I'm having it put in.' So we went over the clinical procedure piece, and I said, 'It's because there's so much tumor in the area of your bile duct, so it's [bile] backing

> up and that's why you're becoming yellow.' Well, as he's looking at me, he *fainted*! [*After describing the distress of that part of the scenario in the waiting room and how the episode made her feel, Sarah went on…*] He finally came around, and I said, do you understand what I have just told you? And he said, 'You have just told me I have cancer around my bile duct…No one's ever told me that. No one's ever told me why I'm so yellow. The doctor just keeps telling me, 'it's just part of your disease.' So [the patient] he's thinking this is *supposed* to be happening because of the disease; *not*, this is happening because my tumor is growing and I am getting worse (FG2S293).

This scenario vividly illustrates the need for integration of hearing and interpreting the story of ILWPC. The narrative underscores the complexity and comprehensive nature of care that is involved in the process of consolidating information—in a discerning manner—in order to prepare all the primary characters of the *person's* story in a supportive, meaningful way. The next theme then, is a description of how the foundational processes of Themes A1 and A2, "*presencing*" and "*discerning*," are manifest in preparing for the hard work of actually *preparing* individuals for palliative care to support their story as they experience transition and life in "mortal time."

Theme A3. Supporting story: Setting the scene. *Preparing for mortal time*

Nurse participants frequently mentioned their role of preparing ILWPC for eventualities, seeing that as part of their responsibility in enhancing the person's capacity for coping with the anticipated effects of progressing illness. This responsibility for care often was noted in the form of actively building on initial assessments gleaned from "*presencing*" and "*hearing story*," and then responding appropriately to ensuing discernment of the individual's and family's readiness to transition. In gathering and integrating facts about the individual—their beliefs, values, social situation, potential sources of support—along with the process of determining their understanding of the clinical aspects of disease progression, there is enhanced consolidation of information crucial to "setting the scene," or *"preparing for mortal time."*

A3.1. Gathering and integrating facts

Sarah's story (cited above in A2.4) of the gentleman with progressive gastrointestinal cancer, illustrates in a powerful way how important it was for her—in the roles of discerning listener, interpreter and teacher—to be aware of the clinical facts of the progression of his tumor growth and the significant effects of the location of the metastases. But her story also emphasizes how important it had been to seek out both the patient's understanding of language used (or *not* used) by health care providers, as well as his grasping of the "bigger picture"—not just about the surgical treatment and its implications—but about what this advancement of disease and the jaundice as a symptom actually meant to him in terms of his own storying and "mortal time" awareness. Sarah found herself having to integrate this knowledge first for herself as a framework for her interaction, and then for the gentleman for whom she was caring. This nursing role of integrating many dimensions of care fits with her comments: "a patient's family will come back to us to say thank you for being so honest with us because that is what we needed" (FG2S442). Other participants identified how they feel compelled to advocate for patients and families by helping to ensure that they understand the truth about their situation (e.g., K139; D653; E339; FG2J684; FG2V563).

In gathering the facts, reviewing them again, and integrating where people are coming from in their understanding of the situation, Jenna noted that "we were able to kind of put it all together for them and they were able to have a better understanding…

becoming more accepting of their situation" (J533). In the situation she used to illustrate the process of acceptance, her role with patient and family had involved planning a repeat visit, then looking at scans, explaining reports, and listening to the memories of a previous "really ugly death" (J550)—a death in the family that had to that point negatively influenced their readiness for palliative care.

In the context of the discussion in Focus Group 1 about whether or not it is appropriate to work at *shifting* decision making to a perceived realistic treatment direction, Mary noted that "in some cases you need to try and make sure they understand *why* they're making that decision. I'm not sure it's necessarily trying to *shift* their decision as much as perhaps gaining an understanding of *why* they've made that decision …making sure *they* understand the full implication" (FG1M218). She went on to explain her comment from the basis of a patient narrative. Knowing the patient *did* fully grasp the potential outcome, and then listening to the patient's reason for deciding on further treatment against the odds of minimal benefit—a decision that she could not imagine making for herself and one which she found *difficult* to accept—helped in her response as the nurse. Knowledge of the patient's goals also helped strengthen her ongoing relationship with this young mother who had chosen to spend less time with family—her home being rural and not close to the treatment center—in the hope that further treatment seeking would produce either a miracle or a legacy of determination.

A3.2. *Relationship building*

As can be gleaned from the preceding category, the sharing of truth based on an integration of knowledge and options available is consistently provided in the context of caring and relationship building, so that the personhood of the ILWPC can be respected.

Nurses in relationship with ILWPC are developing a sense of mutual trust, and are encouraging people to use their personal resources and past history to contribute to the unfolding of current story. That process involves values clarification and informational support on the part of the nurse to help persons prepare for their future. Kristen notes the importance of trust as both antecedent and attribute of this category (Kr1175). She had described her role as a primary care nurse as being "the person who makes sure that happens" (Kr31). By that, she was referring to the treatment plan that had been decided upon, and how her role as the primary contact/resource person focused on guiding the patient through treatment, providing and/or facilitating the teaching, counseling, liaising, and other care provision that is needed (Kr26), sometimes on a daily basis over a period of months (Kr194). As noted earlier (A2.4.5), Kristen's story of the 24 year-old patient underscored that "because of my relationship with this young girl" (Kr215) (i.e., a *trusting* relationship) the patient's mother requested that the nurse rather than the physician—who did not see the patient frequently and knew her less personally—explain the information and situation to her about palliative care. Mary agreed. Preparing ILWPC for the transition to palliative care goals is often "a little easier if you've had time to develop that relationship" (M542).

The notion of relationship as facilitating in the preparation of persons to process end-of-life issues was a salient dimension of Jane's story of a family that was not prepared to have a DNR (Do not resuscitate) order left in their home. In the end, it was only as *she* came to trust the family's decision making—though originally a decision not to have a DNR order was perceived by Jane to betray her professional sense of responsibility—that she was able to support their preparing for and living *their* story. In other words, she was giving greater import to *their* story, rather than the story she and her peer professionals may have felt could—or even *should*—be written. (More of this narrative will be shared in Themes B1 and B2.)

Others talked about the significance of the trusting relationship as an antecedent to the next dimension of the process (e.g., "There's a certain amount of skill at being a good active listener, providing education, and picking up on those clues that that patients give out that allow you to talk more about palliative care" (D880)). They indicated that a context of caring and trust improves receptivity in others if there is opportunity to either "plant seeds" or "open doors" (e.g. "plant the seed and see the growth" (FG2S832; FG2V506)) to further discussion when individuals and/or their family members indicate readiness to seek and/or hear more information, especially if they have to make treatment decisions. That open invitation and willingness to follow the patient's lead may prepare the way for connection even months later (D653).

A3.3. Opening the door and using opportunities

Many of the participants emphasized their role of using opportunities to psychologically prepare individuals for issues that would challenge them as illness progressed. Katie described this in terms of empowering individuals:

> They've just never known that they can have a say in what they want to do, and to hear someone say, 'Yes you do. … get people's input and see what your family feels…but ultimately the decision is yours, and we will respect whatever you do,' gives them an option, it's like it lifts the burden." (K656); "You're empowered to tell your doctor that you want to do what's best for you in the time you have left, and for some people, it's *not* having treatment" (K675).

Vanessa described a situation in which she had taken initiative to speak with a woman and her family because Vanessa had integrated cues from the health record (i.e., the patient had declined surgery, had need for improved pain management, was undergoing current palliative radiotherapy, and that the oncologist had discussed disease progression and no possibility for medical cure) with the patient's social situation (i.e., need for home care, family having to move in with her, numerous other challenges related to aging) and a stated goal by the patient for "quality of life." Based on review of the progress notes and input from other care providers, Vanessa had also observed an absence of physician discussion of options beyond the radiation. "What I was trying to do was get this lady seen by one of the pain and symptom physicians through the palliative care program. So I opened the door to talk about palliative care…I felt it was time we had that discussion" (FG2V506). She described the outcome of that opportunity to 'open the door' as the patient and family being "very much for palliative care," and the physician as being "okay with that," after she had let him know about the interaction with family (FG2V510, 515).

Some of the nurses described specific ways in which *maintaining* "an open door" was accomplished. In the context of discussing integration of facts of disease progression and deterioration of the patient's condition, and times when "they stop me dead on, and it's obvious they don't want to have this conversation" (E166), Emma referred to "leaving the door open for it" (E173). I asked her how she would go about doing that. She explained:

> If they say they want to continue on with treatment and they don't want to discuss this right now, I just say, 'that's fine, but please know that at any time you want to talk to me about this you only have need to call me, or just give me some indication with our further discussions.' I just always make sure that they know they can reach me (my voice mail is there and if they think at three in the morning that they really want to leave a message, that's okay, you know?) ....and I'll often speak to their family—if they feel that they are ready to—to encourage them to

> speak to me as well, so that the family is not bearing that load themselves (E179). I support the family's wishes and I respect their [family's] wishes, and make sure they know that the services are available to them if they want them (E209).

Others spoke of "planting seeds," "having grace time," using "baby steps," and facilitating transition as a "gradual process" (e.g.FG2S855). Recognition that the work could often be done incrementally according to patient and family receptivity was a common understanding expressed by the participants. It was also evident from this sampling of informant-respondents that there is a *matrix* of activity for the nurse in setting the scene for, and then supporting clarification of how ILWPC want their story to unfold given the processes of evolving readiness and understanding of what that might entail.

A3.4. Teaching and normalizing

Education is crucial to the theme of supporting storying through methods of preparing patients and families. The participants consistently included reference to the need to support people both by acknowledging the normalcy of feeling uncertain and other experiences inherent to transition, and also by clarifying contextual values and other influencing factors on their experience of living with advancing cancer. These interventions included ascertaining their understanding of the illness and/or health care provider communication about it and by providing information that could then empower ILWPC to make informed decisions and use self-care strategies to enhance their self-determined quality of life. Repeating information and providing supportive processes as often as needed to achieve QOL outcomes was also identified as significant (e.g., D129, 217, 227, 413, 424; FG2S293; K205; K1178; E212; M539; M 549; M619; FG1M328; Kr41, 442). Sarah's narrative noted above (FG2S293, A2.4) also reflected the ongoing need for teaching and explication as an antecedent for the transition in thinking that individuals need to prepare for palliative care goals.

This category is characterized by attributes that contribute to tension and distress in nurses. Some participants noted how "the teaching and orientation we do…is really critical to these patients" (Kr40), that "all the pre-planning is done up front, generally because we do so much counseling up front" (Kr552), and "we educate them so well because they need to bring things to our attention" (Kr442). Mary speaks of this approach of being responsible in preparing individuals for most predictable possibilities or eventualities as being similar to "cancellation insurance" (M537; M171; M550; FG1M328), as giving patients "the opportunity to feel more comfortable because you have normalized it" (M565). But it was evident in both focus groups in the discussion about this issue of normalizing through using opportunities to teach and prepare patients, that other nurses felt they could not "go there," particularly if the patient was recently diagnosed (e.g., "I would not want to go there," (FG1Sp 295 & 333); "I would have a hard time making it sort of an agenda" (FG1Sp260)). In contrast to Mary's view that the patient could be made more comfortable through up front discussion, Spencer's rationale had to do with the context of altering perceptions of hope. Some linked the hesitation with need for cues of readiness behaviours (i.e., waiting for the patient's lead (FG2R547), versus *taking* the lead to "open the door" (FG2: S308;V492; J676). More about the tension inherent to this dilemma is explored in Themes B1 and B2.

Mary's story of the person who heard it all from the health care team at the beginning but was still not ready to listen and would tune the team out if mortal time issues were broached (M410) highlights interconnectedness between the categories of this Theme A3 as well as how the issues of timing and readiness are not always predictably enhanced by teaching up front. Rachel pointed out another salient issue related to timing: transition is a process. “Information may be there for the moment, but they’re not retaining…it can’t all be absorbed at one time” (FG2R616). It would seem then, from the experience of these nurse experts, that regardless of the decision to provide teaching “up front,” if patients were not in a frame of mind and spirit to deal with mortal time issues, attempts to shift their thinking were perceived by the care providers to have been either “unsuccessful” (i.e., in accordance with more concrete outcomes and external expectations, such as acceptance of palliative care services), or “successful” from the perspective that in spite of information provided, a patient’s personal decision to postpone or reject those services has been honoured and respected.

Though four categories of Theme A3 have been teased out of a matrix of transcript data because of their distinctive attributes, they cannot be considered in isolation from other dimensions of what is going on. Again it is evident that they cannot be considered without thought of what has been established through the previously identified themes of presencing and discerning behaviours. (Jenna’s story—mentioned in category A3.1—illustrates how teaching and preparing intersects with Theme A4: “They might not might not come through that door with me right away, but the door has been opened” (J155).) Nor can previous categories be disconnected from the ongoing supporting of the *living* of story as ILWPC “shift gears,” “turn the corner,” or “start going down a new road,” phrases frequently used by nurses in caring for patients in transition.

Theme A4. Participating in story: Facilitating transition. *Sharing mortal time—*

Processing and facilitating awareness

The nursing role in transition involves planning, patient/family education and informational support in order to build on the work done with patients and families in the preparatory phases of transition. Mary spoke of how difficult it was for patients to come to terms with transition:

> Even though we tell them, they don't really think as much about what will happen if the disease just doesn't respond [to treatment]...the feelings that they have of 'changing pace,' or 'changing gears' or 'going down a new road,' or however they word it to me, that's all descriptive of their transition. Some people do it very quickly and other people don't do it well at all—or ever, sometimes (M204).

Mary related that her experience has demonstrated that at times the introduction of palliative care is perceived by the ILWPC as a "giving up on me" (M1263), and that the need to reassure and allay the fear of abandonment is a part of the dynamic of "turning the corner" or "switching gears" (Kr255) with the patient. This phase of the role of the nurse in transitional cancer care again emphasizes the importance of ongoing relationship and presencing as nurses come alongside and process the dynamics of transition *with*, not *for*, the ILWPC.

A4.1. Turning the corner: processing transition and mortal time awareness

Jenna had worked with a man and his family (referred to in A3.1) who were initially focused on treatment intervention; he was having difficulty coming to terms with the advancement of his illness and thoughts about the option of palliative care. As she described her interactions and care interventions, one could infer that planning, informational support and repetition were all effective antecedents to better understanding and eventual acceptance of the need for palliation. A significant part of *his* shifting gears from the focus on curative measures that were no longer feasible given the progression of his illness despite treatment was correlated with her reframing of the information, and working within knowledge of his context of fear (i.e., that he too might experience an “ugly death” which is how he remembered the death of his wife). One of the patient readiness factors that Jenna and others observed related to more direct questions about how the illness might unfold (e.g., “What else is there?, How am I going to die?” (J94)). Another nurse said: “People have asked me ‘what is it like to die of lymphoma?’ I use the crystal ball thing…I don’t know how, I can’t tell you that, but I can let you know some of the potential things…I let the patient direct what they need to know” (Kr1115). Processing these difficult queries *with* the individual is essential to supporting them as they process the transition of letting go of thoughts of medical cure while entering into a fuller awareness of what it is like to *live* in mortal time.

Kristen also shared that with one person “the issue of her dying didn’t come up all the time. We talked about ‘What are we going to next?’; but we got to the point in the last few weeks that [we realized] there aren’t going to be many more ‘nexts,’ so our conversations have ‘switched gear’” (Kr 250). It was at this point that Kristen realized that she had ‘switched gear’ herself in that she was now thinking in terms of “palliative” as opposed to “supportive” care as she processed the transition with the young woman. She had even used the phrase “maybe it was partly me” in reflecting on the use of language, meaning, that is, that she herself had been holding back on using the term “palliative” (Kr273). This was a self-observation that occurred during the interview, and a sign of professional maturation that will be explored in B2.3.

Mary further articulated the nurse’s role by describing what processing with the family is *not*: “I don’t think that at any point the doctor, the nurse, the social worker, or whoever's doing these discussions is going in and saying, 'This is what you need to do.'" (M1247). Rather she (and others) described a seeking out from the ILWPC of "What would your wishes be?" and " 'What can I do for you?' You know, 'What do you need for us to do?'" (M1251; D1094). Listening to the answers is essential. Kristen told the story of a woman who "knew she was going to die of her disease, and her focus is on quality of life with her son for the time she has remaining. I've talked very openly about palliative care with this family…she's quite remarkable" (Kr412). In contrast, Mary recounted the response of one woman who made it clear after palliative care had been offered as an option that the patient politely indicated: " 'I've heard what you're saying. No, we're *not* going that route.' She was very clear. She was very delightful" (M343). So, as Mary's story illustrates, when "going down a new road" is *not* the route of palliative care that care providers might envision is the "appropriate" or conventional way to go, what ought the nurse to do? (Category B1.2, "respecting patient choices," will explore the role of the nurse in these sorts of circumstances.) Mary's insights are an important segue to the next category of "*coming alongside: facilitating transition.*"

A4.2. Coming alongside: facilitating transition

Nurses frequently clearly described their role in providing support to the *living* of story when the ILWPC had recognized that they were "going down a new road." In the relationship with the young woman that Kristen spoke about (A4.1, Kr242), she had gone on to say that she had made referrals to other resource persons from whom the patient could receive assistance (i.e., social work, spiritual care, and the palliative care program (Kr 317)). This facilitation of transition incorporated the acts of care provision to ensure adequate symptom management, liaising, guiding, collaborating, referring and providing links with helpful resources, and assisting patients to reframe their treatment goals. Dawn recounted a situation in which a woman who lived alone with few apparent resources had indicated her desire to die at home: "'You know I want to stay at home'…so we talked about what are her resources that would enable her to stay at home. We sort of developed a plan together, a care team together" D503).

In the context of third and fourth line treatments having failed ILWPC, Sarah identified inviting patients to reiterate in their own words what they understood the physician to have said as another occasion when it is possible to "plant seeds." Sarah added that because there are often needs that bring the patient to clinic for supportive care "there is some grace time, you can do this very gradually" (FG2S855). She was referring to the need to reinforce for the patient that though third or fourth line chemotherapeutic intervention with antineoplastics had failed to stay the progression of illness, other interventions or options related to palliative care and quality of life could be provided.

Dawn noted that the timing of educational preparation was in large part dictated by the urgency of need, and that much of the content of teaching and informational support was anticipatory as well as reactive (D220). Her discussion about the issues and work of transition reflected the need for individuals and families to "take care of business." She used, for example, the scenario in which an individual may be vulnerable because of brain metastases. Thus, awareness of potential cognitive incompetence may prompt the need to broach end-of-life issues early enough for the ILWPC to address any "unfinished business" while they are still able to do so (D232).

Assisting patients with goal setting and prioritization of this important work of coming to terms with their personal affairs is intricately connected with their understanding of just where they are in terms of their life story. If ILWPC do not understand the truth of their situation, it is less likely that they will be "ready" to enter "mortal time." In coming alongside and facilitating the business of transition in sensitive ways, nurses find themselves frequently dealing with issues of personal and professional integrity.

The next Theme, "Doing the right thing right," introduces Part B, the meta-framework of nurses' work in transitional cancer care. The theme provides explication of some of those moral and ethical elements that nurse participants identified as both infusing their work and challenging them as they worked to respectfully support the integrity of personhood for ILWPC and their social families.

Part B: The meta-framework for the narrative

Theme B1. Enabling integrity of story. *Doing the right thing right*

One of the themes that emerged early and consistently in the interview process was a recognition that nurses desire to do the right thing. At this juncture, a lengthy but rich narrative will be used to introduce a number of the categories in the next two Themes. Though I will abbreviate the introductory part of the narrative, I believe that some significant portion of its integrity would be lost if the narrative were quoted piecemeal for the sake of analysis. (In fact *many* other narratives in the transcriptions deserve similar treatment, but for the sake of brevity, have not been quoted in this manner.) In the focus group where this story was shared, there was empathy and emotional connection with the others in the room—an interpretation based on their attentive and reflective body language and gentle probing—as Jane shared from her struggle to balance the needs of a particular family with the professional self-expectations that often accompany transitional cancer care nursing. It is a moving story of Jane's learning more about being sensitive to the uniqueness of personal history, of respecting the principles of self-determination, and of trusting the patient and family as the authors of their transition narrative.

Jane introduced the exemplar as one that taught her much about the tension and complexity of whether or not we do the right thing in waiting—versus taking initiative—to introduce issues related to end-of-life decision-making: "an incredible family taught me a lot about this issue, so I do take greater risks since I have been with this family" (FG2J707). In trying to meet her professional sense of obligation to prepare a family for a home death by having the issue of resuscitation resolved and "covered" by having either a physician order for "no resuscitation" and/or a letter of anticipated death in the home, Jane "would gently bring this up for discussion every time I went" (FG2J724). The family continued to delay, and though the Rabbi had been called in and the issue discussed, Jane realized that to wait "one more day," at the request of the wife of the dying gentleman, would mean that the effort would become moot. In her nursing judgment, it was evident that the patient was imminently dying and may not *have* any more tomorrows. As Jane related the story, another nurse in the group probed gently by asking "how did you feel?" (FG2R756). Jane talked further, then, about feeling like she "wasn't a good nurse" (FG2J758). Shortly before being asked this question, Jane had revealed her own expectations of a good nurse: "if I'm a good palliative care nurse, I'm going to have all these things in place" (FG2J731). But she also demonstrated skill in using reflexivity, discussed further in Theme B2, as part of her practice:

> I felt like I wasn't a good nurse. That was part of what my feeling was. But there was another part of me that just kind of trusts what people are doing. So I went with that and didn't push it. So I left. And sure enough when I talked to them and went the next day, he had died. At two in the morning he had died, and she called the ambulance and they rushed him and did all the pounding on the chest, and so on. So when I met with his wife we talked about it. And she *thanked* me for not pushing her. (S: Wow.) She said [*Jane's voice emotional*]: 'If I hadn't done that, I would not have felt like I had done everything I could do for him.' (S: Right.) It was not a traumatic thing. It was not how...for me that would've...I thought, you know, why would you want to see somebody be pounded on and rushed to the hospital? For *her* it was not a big deal and it was *important*. I didn't find out until that discussion they were holocaust survivors. [*A softly whispered background comment from another participant:* Oh-h.] We hadn't talked about it throughout the two-week period that I got to know them. She was a...they were both holocaust survivors. So we just thought...I thought, you know, we needed...they *needed* to do that. [*murmurs of assent audible from others*] Not that I don't judge myself, but I was a little harsh on myself because there was this gut thing that was saying, 'You have to talk about this, but don't push it.' I'm… was really *grateful* I hadn't pushed it. I just had a whole different attitude about what was right and what was wrong after that. (S: Right.) There's no right and wrong about death. Everybody has the right to do it their way. So that's freed me up a lot to have discussions in a different way with people (FG2J758).

Nurses have certain perceptions about what they "need" to do if they are "good" nurses; but Jane's story is a wonderful and insightful exemplar of how we learn to question our perceptions. Expert nurses in this study thought about their responsibilities in other complex ways. Vanessa's story cited earlier in A3.3 (FG2V478) that illustrates the taking of initiative to "open the door," was not based on an attempt to merely shift the patient's view of the 'big picture' because it was deemed that the patient did not understand or was unrealistic about matters of mortal time. Rather, the decision to "open the door" was rooted in a desire to validate the elderly woman's already expressed wishes, and then clarify them in the context of possible options related to palliative treatment. Mary expressed how important it was for her to learn that if patients were *not* ready to transition at a time that others might presume appropriate, the team needed to ascertain *why* the patient and/or family was having difficulty with the transition (M858; FG1M220). It would appear that this concern was founded in a felt obligation to ensure that the patient was both known to the team as a 'person' and that their individuality was respected, and also that the patient had been given all the necessary information along with explanation to ensure understanding, so that an informed decision was the outcome. That these concerns and others should matter to nurses was evident throughout the interviews and underscored the significance of this Theme.

B1.1 Doing the right thing right

Jane's narrative and the other participants' observations noted above exemplify the striving of nurses to "do the right thing." Many situations in practice involve either moral distress (defined in Chapter One) or moral dilemmas because conflicting demands have been created by the need to address conflicting moral principles. Each of the participant nurses' reflections and actions reveal that nurses are dealing with moral and ethical judgments that must be integrated into their everyday practice. In the introduction of her interview and the description of her role, Dawn indicated that she had been drawn to participate in this study because "in your practice, you often wonder, 'am I doing the right thing?'" (D44). She went on to comment that "how you talk to people about palliative care is something we are all wondering if we're doing the right thing" (D62).

B1.1.1.*Respecting choices*

Participants (such as Jane and Mary, introduction to Theme B1) consistently reflected a commitment to affirm the ethical principle of patient autonomy or self-determination, ensuring that the choices that people made about their health—including end-of-life decisions—were based on sound, comprehensive information. (Aspects of nursing practice such as listening, respecting personhood and contextual factors, discerning, understanding, teaching and informational support, have been noted throughout Themes A1-A4, and are also integral to the discussion at hand.) Mary reported the distress a team shared in honouring the wishes of a young man with small children despite their angst about how his young wife would be able to cope without palliative care services that he was not ready to accept. (In order to respect her husband's decision, the patient's wife would not consider having a health care directive or letter of anticipated death in the home.) Mary broke down in tears as she recalled the poignancy of the feelings she had the day she took the phone call from his distraught wife, because he had died at home and she had called "911." The outcome related to Mary's previous concern had been actualized; that is, the need to fulfill a felt responsibility to prepare the family by addressing anticipated needs in the event of death at home had been in conflict with a professional respect for the couple's choices (M427-455). (The consequence for Mary arising from this story is noted in B2.2.)

Dawn noted: "We have to recognize that patients' choices are not *necessarily* the choices we would have made in that situation," and, "to respect patients' choices, I think that's a really important thing; so, sometimes you have to adjust the type of care you're giving based on the patients' responses and choices" (D566; 583). Mary had noted a similar value when she said: "it was not as I would have planned it, but it wasn't my life to plan anyway" (M498). Mary also shared in the first focus group how difficult it had been to respect the choice of a young woman who was guided by her belief as a Jehovah Witness to refuse transfusions that could have clinically provided respite from her disease: "that was very difficult for the whole team…it's not always easy taking cues from the patient and doing what they know is right for them" (FG1M487). Respect for self-determination is also the underpinning theme of Jane's exemplar used in the introduction of Theme B1. In the situation with the gentleman who had refused radiation therapy for spinal cord compression, Jenna revealed the moral distress that may be experienced when nurses believe the patient may be making a decision that would not be considered "best practice." Jenna noted that that she had "wanted to give him more than he wanted for himself," (J427) and that even though he gave her permission to be satisfied with his decision, she "really wasn't" (J420). As the data indicate in this study, the actions of these nurses are admirably supportive of the value of choice as they work to respect informed choice—even when that added to the emotional burden of caring that these nurses bear.

B1.1.2. Beneficence and distributive justice

Another dimension came through. The unique needs of ILWPC, and the nurses' attempts to care through acts of kindness and amelioration of suffering, must be balanced in context of a system that must also consider universality and justice, recognizing that resources are not limitless and must be fairly distributed. At times this left the nurse feeling frustrated and in moral distress as the conflict of "goods" had to be integrated into practice. In the case above (J420), Jenna's frustration partly came from recognition of the irony of circumstances: " I probably struggle with it because there's so many people that we *can't* help with *anything,* even short-term; and then you've got the other end of the spectrum where you *could* do something [and the patient refuses treatment]. You kind of pull your hair going, ah! This isn't fair!" (J504). Some examples of other perspectives regarding justice values included:

1) individual benefit for a patient receiving palliative chemotherapy versus systems criteria for admission to the palliative care program which precludes such intervention (D357; J363; Kr1530)
2) nurses who feel the peer pressure of time constraints (D750; K684, 1075, 1107; J242;)
3) peer criticism or lack of collaboration and support if nurses respond to a patient or family who needs more time—especially if they need to discuss end-of-life issues—while other patients are waiting to be seen and peers do not pick up to accommodate the circumstances (J290; D752; K1066)
4) some areas having adequate space and/or privacy to do the work, while others did not (J347; D756; K684).

B1.1.3. *Valuing dignity and personhood*

Nurses in this study consistently expressed a desire to provide safe, competent care that is respectful, and preserves the dignity of the individuals for whom they are caring. Again Jane's exemplar clearly reflected these values. Jenna expressed concern about whether it was the "right thing" to express her emotion in tears because such nursing action may affect the confidence or hope of the ILWPC (J721). With my gentle probing, Jenna's reflection about the issue helped her to place her action in perspective as a beneficent act rather than one which was harmful. It was apparent to me, however, from her questioning of her own behaviour that she was *considering* the potential for either a beneficent or maleficent outcome, and that she needed to parse that out of her tearful and empathetic response to a particular patient who had received "bad news."

Other stories of dissonance with *patients'* decisions was evident in many of the stories recalled by the nurses. Mary recounted a moving narrative about a woman who opted to go through bone marrow transplant, not because she wanted to do so for herself, but because she wanted to die knowing her husband could live "guilt-free" because she had done everything she possibly could. She had confided in Mary, sharing her true desire *not* to go through with treatment and that she would "rather be at home" (M928). Yet, she had not wanted Mary to talk with her husband about her *real* reason for undergoing such risky, aggressive treatment (her chances as described by the oncologist were less than 50% for survival, and less than 10% for non-recurrence post treatment). As Mary spoke of her feelings in response to that confidential information, she reflected on this experience of sharing mortal time:

> I found that really hard. And yet I also, um, found that I really had some weird sense of admiration for what she was doing because if he felt that strongly about it, she was probably right—he would have lived for at least part of his life wondering… 'what if we'd done,'…you know? (M952).

After my commenting on the level of trust that this woman seemed to have had in Mary, she responded:

> I know, and the scary part is that for a period of time it runs through your mind, 'I *should* tell him. You [the patient] should *stop*' (M980)….Talking about these big decisions—particularly end-of-life decisions—you have to be so careful not to put your values onto someone else. That's often the hardest part of the whole job of talking to people about dying (M990).

It seemed to me that Mary was respecting this woman's dignity and not merely her unusual decision. In revealing her reasons, this woman had enabled Mary not only to accept, but to understand, admire, and respect the choices—and consequently, the *person* behind the choices.

Vanessa's story of parents who wanted to protect their 18 year-old daughter from the truth because she had become depressed after bad news in the past, demonstrated the dilemma of the nurse's value of respecting the personhood and maturity of this young woman—she needed to be able to make her own decisions and write her own story—while also trying to respect and understand the pain of her parents (FG2V875). Vanessa's narrative brought to the fore another source of conflict, demonstrating again the interconnectedness of the categories and themes inherent to transitional care. The story leads naturally to the next category.

B1.1.4. Truthtelling

Truthtelling is another significant dimension of moral and ethical challenge in cancer care. While understanding the parents' belief that telling their daughter about the extent of the disease progression might bring emotional distress and changed hope once again, Vanessa had also pointed out that knowledge of the truth might also allow their daughter opportunity to "say her good-byes and leave some kind of legacy behind. (*said reflectively*)...She was a very artistic person" (FG2V913).

Expert nurse participants such as Vanessa validated a perspective commonly but not exclusively held by individuals in Western cultures that it is much more distressing to deal with illness if unprepared for it than to deal with the distress of the truth. Though most participant nurses live with this societal lens of truthtelling in health care matters, they also demonstrated their awareness of the need to respect cultural diversity, religious beliefs, and individual personalities when faced with ethical and moral issues related to truthtelling. Their stories emphasize the seeming contradictions—or perhaps complexities—surrounding the sharing of truth.

The narrative that Vanessa shared in the second focus group (i.e., FG2V913) was quickly followed by the personal narrative of Sarah, who told her story of a teen sibling who died of cancer. She shared that her parents had concern about the physician telling their son the truth about his ominous disease progression, because they feared his last weeks of life would then be clouded with "depression, or lost hope" (FG2S988). Sarah recounted with deep emotion how her brother had known because of physical symptoms he was experiencing that his illness was advancing even before clinical confirmation. She described the agony her parents went through for two days before they followed the physician's advice and then their hearts. The outcome for this family had been an observation that this young teen "was better with it than anyone else…*We* were all losing it but he was okay. I wish I had had opportunity to talk with him about how he had gotten to this place of acceptance…*(now there were few dry eyes in the group as tearfully she also expressed)* …had she [the physician] not said those words, I would not have had the opportunity to tell my brother that I loved him. I had that chance and he heard me" (FG2S1007). This had been shared in the context of Sarah's explanation that in her family, saying "'I love you' was not said…enough" (1022). Her recounting of her family's story, including the grappling with truthtelling and other related issues, had had profound impact on her sensitivity in caring for ILWPC. (This last comment is made not just because Sarah had early in the interview indicated that her personal experience had drawn her to cancer nursing. The deduction was made as I reviewed the totality of the transcript.) For instance, in another section of the group discussion Sarah recalled feeling the need to discern validity of the care team's assumption that an elder—from a culture in which the family/community takes on the health concerns of the ILWPC—might *want* to know his own information:

> I just wanted to 'test the waters'— 'cause sometimes we've had families that have kind of been deceptive—to be clear that this was truly what *he* wanted. And I said 'Your family has shared with me that it is [because of] your culture that you don't want any information. Is that true? Do you want me to tell you what is going on, or what is okay with you?' And he told me he *didn't* want any information. Again, I think that's not something I would have done as a new nurse or even a beginning oncology nurse. There's no way I would even think that challenging that would be okay for me to do (FG2S655).

Spencer spoke of one situation in which she too learned something more about truthtelling. A patient's wife had expressed distress that her husband would not communicate as his pancreatic cancer quickly advanced; she was left feeling that they could not be open about the truth of their situation, sensing he was denying the seriousness of the circumstances. Yet, when he died she discovered that he had meticulously taken care of business and had written letters to family members (S187-211). He had simply chosen to deal with it in his own way; and, in retrospect, his wife had experienced the righting of a perceived wrong. In contrast, Spencer described what it had been like to observe another family in grief where also there had been no talk openly of palliative care or impending death in order to spare the *patient* from the truth. In this situation, fear, apprehension, and much anger had been the overt outcome (S146-159). Memories of such experiences may contribute, as antecedents, to a felt obligation of nurses to advocate for patients so that more positive outcomes—for patients, their families and their care providers—can come from living in mortal time.

B1.1.5. Advocacy

The role of advocacy for the patient when there was disparity between the *family* wishes and what the staff thought was "right" was a concern also identified by Emma: "I think it was cultural…the children didn't want their mother to know. I had to really advocate on behalf of the patient, that she had the right to know what was happening with [her] health…The family was very angry about that…that was probably one of the most difficult times" (E340). The outcome in this situation was different from the circumstances cited above in Sarah's story. Though there was still an underlying premise that "the patient has a right to know," Sarah had been able to be open with the patient about clarifying his wishes, while still respecting those of the family; whereas, in Emma's situation the family had felt alienated. Finding that middle ground when dealing with competing needs for the sharing of the truth is challenging, and insightful and sensitive nursing agency is required. Having explored what it meant to have sensitivity to the values of the persons for whom nurses care, Mary's following comments make a helpful segue to the next category:

> You can't make sense of it [sensitivity to the values of others] until you've lived it a little. And you don't necessarily have to learn it through your patients. You can live it through the nurses you're working with….hopefully that's a less painful way. That's why it's so important to share these stories with each other, I think, and have a good supportive team approach … It doesn't happen everywhere, but …(M1008).

B1.2 Creating or shaping solutions

Mary had touched on an important antecedent to the need for nurses to practice within the professional ethical code and to work together to diminish moral distress when principles are in conflict. Learning from case studies and the sharing of stories, team assessment and decision making, debriefing and support for one another, all contribute to acknowledgement of inherent challenges to the role while creating an environment where solutions can be developed and moral distress lessened (D1389). Resource limitations, time constraints, and systems of care were identified by a number of individuals as potential barriers to optimal care. Their influence of particular barriers seemed to be felt more dramatically in environments where there were space constraints and relationship challenges, and little nurse control over patient scheduling (D752; E408; K1046; M698). One can infer this from the contrast in expressions from two participants. One was working in a supportive environment and team where nurses are able to function with considerable control over scheduling their workload, space allocation, and where there was peer respect for the need not to be interrupted with a given patient (E415). The other worked in an environment where there was a system of greater accountability to a group of physicians and *their* scheduling needs rather than to the needs of patients and peers, where available space was a challenge because of numbers of patients required to be seen by a group of physicians, and where the sense of "team" was negatively affected by these felt pressures so that there was little evidence of support for one another as nurses in the attempt to respond to individual needs. Examples of contrasting verbatims follow:

> Sometimes I burst into tears, and sometimes I just need to talk to my colleagues and we try to work it out....sharing is a huge thing. We support each other all the time (Kr 661, 731).
>
> It's hard to ask your peers for support. You know they're busy; but there's also not always the support (J247). I'm not sure why it [lack of peer support] happens. I don't think nurses are as good to each other as we're led to believe...so you end up working overtime and compromising your home life...It just doesn't seem right in the nursing world, not willing to give that extra help that we all need (J282).

These verbatims are reflective of the values that will be further discussed in Chapter Five.

In addition to talking things over with peers and getting their support for timing and appropriate decision making, nurses also spoke of rehearsing things in their minds before exposing the patient to bad news (e.g., in sharing diagnostic results), or in follow-up to news from the physician. "There certainly is emotional and mental preparation before going into the room…and making a phone call. I guess I think about how the conversation might go, I run it through my mind" (Kr689). Jenna stated that "you have to do lots of self-talk and almost rehearse—then you know you're not going to stumble and bumble though the whole conversation—maybe just parts of it (*said with a smile*)" (J700). Thinking about ways in which to share bad news with the least harm to the patient was mentioned by most of the participants as an area of care where they wanted to do the right thing in the right way. Preparation of the physical environment, ensuring that privacy and quietness was available, and that peers had been advised not to interrupt were noted, for example, in Emma's description of how to facilitate the work of transitional care (E396).

Implications for the joint responsibilities of nursing and non-nursing managers, administrators, educators, researchers and other professionals who share the challenges of shaping the outcomes of health care through organizations and other systems will be discussed in Chapter Five. But a further area of potential conflict and distress noted by the nurse participants, one which led to the extrication of category B1.3, and which also needs to be managed by systematic and organizational support as well as individuals, follows.

B1.3 *Differentiating roles*

Tensions regarding role expectations of each other in the nurse-physician dyad, in particular, were touched on in the individual interviews, but highlighted in the focus groups. This is one work relationship that has been fraught with challenges that have been studied by nurses, physicians and sociologists for many years. Cancer care settings have not been immune to such challenges.

Understanding of the nursing role in transitional cancer care varied among participants, especially in the area of initiating open discussion of disease progression and the bigger picture of what such progression might mean for the patient and family. It was evident that nearly all the nurses felt that they should be involved in providing information, not just *responding* to need, but also in *anticipation* of it. Furthermore, they identified a role in facilitating supportive interventions with palliative care as an option to be discussed. (Some differences of role delineation between physicians and nurses have been discussed in the context of presencing (Theme A1) and discernment (Theme A2), especially in relation to use of language.)

In one interview the nurse shared that in their team it was nearly always the nurses who provided information about advance health care directives, palliative care and other end-of-life discussions. In fact, in describing the roles and positive feelings about two different physicians, she compared their approaches to palliative care.

> One can be fairly direct and talk about dying, but then will leave the room for me to take over the conversation and is *grateful* for it…makes no bones about it, you know? Um, but the other one has a really hard time to say that or initiate that discussion with the patient. I can't think of a case where he's actually mentioned the palliative word—the 'P word.'
>
> Researcher: So is it sort of an *understood* team function that you will then pick up on those conversations, or…?
>
> He and I have never had that discussion and I've worked with him for [an extended period of time]. …We're just in the room with the patient and he'll explain that their disease is progressing…and he'll say 'we could do more treatment,' and he'd suggest a couple of things. And I'd say, 'or there's palliative care that's available.' And he'll say 'right,' and he'll talk to them a minute more and then he'll let me talk about it. He just…it's like he *can't,* you know? (E640)

This was the topic of impassioned dialogue in Focus Group 2 as they shared stories of times when nurses felt very distressed that some physicians could not seem to get the language right. That is, they could not, in the estimation of the nurses, seem to share bad news in such a manner that the patient adequately understood its significance (FG2S, J, R & D292, 538). When Rachel was describing her frustration and anger that an oncologist was so vague, several nurses in the focus group simultaneously blurted out "Just tell them…Just say it!" (FG2S & R403), while others nodded in agreement. In response to a question ("How do you deal with the 'physician piece?'" (FG2S475)), Vanessa shared a story of taking initiative when the physician had delayed; furthermore, she indicated that "he was okay with that" (FG2V515), and that she felt that many opportunities for right timing would be lost if the nurse was to wait for the physician to take the initiative (FG2V520). Dawn noted that sometimes it is her perception that "doctors don't always like you offering that option [*i.e., palliative care instead of more 'futile' interventions*] but I feel that it's our obligation to *provide* that. So sometimes I'm the 'devil's advocate' placing that option open" (D1141). When then asked how she saw integration of the roles, she went on to describe several salient points: nurses take the time and may have more flexibility with controlling time; nurses often know the patient's social situation better; nurses are generally more familiar with community support resources and how they can access them for patients; and, nurses tend to function from a more holistic approach in managing care for individuals who are facing death (D1155-1182).

Sarah described the phenomenon this way:

> I only do what I do because of experience and the time that I have grown as an oncology nurse. It's different today than it was when I first started to practice where the physician's word was the law, and I would never 'buck' the physician. Now I say, 'You don't want to deal with it? I will.' And I go and do my piece. That only comes with experience and time, and with positive experience in palliative and supportive care where a physician or a family will come back and say 'thank you for being so honest with us because that is what we needed' (FGS430).

There was not complete congruence with this philosophy or understanding of the nurses' role, however. (It was of interest to me that it was in light of these powerful stories of advocacy that one member in the group became what appeared to be extremely contemplative, adjusting her swivel chair—rocking ever so gently—so that she could gaze out the window at the falling rain. The conversation was intense, so I needed to stay on track with it, but it was a nuance that I wondered, both then and after the fact, if I should have probed gently as to what she was thinking about at that time.) Indeed, one informant shared that in a recent conversation with several cancer care nurses they expressed feeling that the discussion of palliative care and end-of-life issues was the purview of the doctor, not the nurse (M708). She had expressed surprise—even disappointment — by this belief, reinforcing her view with the other nurses that it *was* a part of the nurses' role, though "not necessarily a comfortable part [of the job] until you become adept at doing it" (M716).

The interaction she recounted demonstrated another dimension of the issue. Tension was not just centered around *timing* of the interaction, but also the question of *who* should be the initiator-facilitator of end-of-life discussions with ILWPC. Mary observed with surprise that it had been recently-educated nurses that had expressed this hesitancy, *not* nurses educated at a time when there were sharper differences between nurse and physician responsibilities surrounding the sharing of information with patients about end-of-life matters (M738). She had reflected that less experience and maturity could have been factors that influenced the most verbal nurse's feelings. In an astute way she added:

> I think she just didn't know how to cope. It was more than she could deal with, and that was her way of maybe saying 'I can't do it.' Instead of like the example I gave you before when it was a nurse [with experience] who said, 'If you hadn't offered I was going to ask [for help].' She just couldn't cope with it *again* [because there had been several tough situations in a short time frame]*...not* that she couldn't cope with it at *all* (M768).

Katie added further enlightenment when she too explained that there was not the same consistency in understanding whose role it was to talk about end-of-life issues and palliative care referrals among nurses themselves. In her statement "That's the clinic nurse's role" (K63) (signifying the process of referral to a palliative care program), she was reinforcing an outcome *task*, a *system* of work that limited her perceived role. Yet from so many of her comments and observations throughout the interview, I could infer that she actually *did* spend much time discerning where individuals were in readiness for palliation, and in preparing them for that transition. After describing the enviable privilege that "clinic" nurses have in having privacy to talk with patients, she notes: "They do a tremendous job. Yet I still feel the treatment room nurses are important. We have to make that experience as *...positive* as we possibly can" (K1046, 1147). In this statement she probably captured more of the truth about her role in facilitating transition to palliation, and that patients and families benefited from her interactions as a treatment nurse as much as they benefited from the interactions with clinic nurses. In other words, the differing nursing roles as understood by the system might belie their actual contributions to care of ILWPC. (The fact that Katie had been nominated by her peers to participate in the study lends further credence to my inference about her skills in transitional cancer care.)

The nursing role was further differentiated through team function and relationships. The nature of team functioning was identified by the participants as important to the perception of transitional care outcomes. Contrasts in two teams and how they function can be sensed in the following process descriptions:

> By approaching the whole idea as a team,…and discussing it with them (the physician, other nurses and the social workers), you work it out a lot yourself first (*upward inflection*)… and then it's not as hard to go and discuss it with the patient and the family (M880).
>
> The …doctors that I've been working most with …we usually know and agree at about the same time when somebody's ready, or [that] treatment's not working. The doctors say, 'I'll be the one to indicate that,' to me…but as soon as they've had a discussion, they just sort of wash their hands of it. It's done. We've had it, let's pass this along to the palliative care program. One is very abrupt and you can kind of work around that, and soften it after [the doctor] leaves the room. [Another] one has amazing communication skills and really seeks clarification and understanding from her patients. So she's very good at that. But they both just want to be done with it. We're 'in synch' to a certain point and then they…they stop. So it ends up being myself and the palliative care team that will carry the ball from there (J877).

Team relationships demonstrated the contrasting effects of cohesive supportive environments with those lacking such qualities. Though the nurses were carrying through with more detailed discussion of the palliative care program and services available in both situations, one nurse felt supported in follow up by the oncologists and peers, while the other had to seek that support from the palliative care team to whom the patient was being referred. In nearly all situations that nurse participants found themselves working in, there was need for nursing to "carry the ball" in the latter phases of transition, and these findings will be further discussed in Chapter 5.

Theme B2. Creating spaces for new stories. *Reflecting on mortal time: nurses' stories of personal and professional vulnerability and maturation*

The Oxford Dictionary (1985) defines "reflection" as a process of going back in thought, being introspective, meditating, consulting, reminding or reconsidering. When the person's action of reflection *involves* him/herself, it is said to be "reflexive" (Oxford Dictionary, 1985). *Both* processes were evident in the clarity of the participants' responses to the semi-structured interview schedule, and the significance of this characteristic of expert practice and the nurses' stories will be explicated throughout discussion of the four categories of Theme B2. "Reflection" and "reflexivity" aptly describe how the participant nurses frequently contemplated their role and the enduring influences of interaction with ILWPC.

6.1. Reflecting on the experience of mortal time

In an early interview, one of the nurse informant-respondents made a statement that was reinforced by the narratives of subsequent participants. She had observed that it was much more difficult for her to recall and describe scenarios in which things went "well" or "felt good" for her—"the harder ones always come to mind" (E326). That said, the same nurse was also able to describe the personal satisfaction that was inherent to effective facilitation of a supported transitional time for ILWPC (E455). Common to both of her observations is the underlying process of introspection.

Previous narratives have already illustrated how processes of reflection and reflexivity are closely linked with consideration of underlying moral and ethical values

(Theme B1). Dawn's comment about wondering if she was doing the right thing (D44), Jane's reflection about being a good palliative care nurse and what that meant (FG2J758), and Mary's expressed concern of "worry," along with her question, "If *he* wasn't prepared, how do you [that is, the nurse] prepare the rest of the family?" (M427), are just a few examples. Katie explained that because she had worked in a bone marrow transplant unit and observed that few people made it through the treatment or were actually cured, her personal beliefs about the outcomes for patients had been affected. "When they [patients in outpatient care where she now works] say 'well what would you do?', to be very honest sometimes I know how to answer that and sometimes I don't….When I see people going through bone marrow transplants, I don't know if I would do that. … I just don't know if I would do that… [*voice quiet, face reflective, pause follows*]" (K622). However, still in a manner both reflective and self-aware, she then qualified her comments with the following statement: "but if that's the only hope, then you don't take that away from somebody, right?" (K642).

Another attribute of reflexive behaviour was elicited from the nurses' descriptions of *"preparing self"* before having sensitive interactions with ILWPC, and the nurses' descriptions of ambivalence about broaching mortal time. Some spoke about centering their thoughts, of using prayer, of reviewing the intent with peers to ensure the appropriateness of timing, of rehearsing the dialogue, and of rallying oneself to the task ahead (e.g., E896; J700; Kr689, 698; M525). Laughingly (which was significant in that her laughter followed some tears evoked by a patient's story), Mary noted her feeling that "well you wish you ran a flower shop instead of worked as a nurse…[asking] 'Why am I doing this?', or 'maybe someone else could do this,' or something. But then you sort of rally yourself" (M519). Emma noted a similar feeling of wanting at times to avoid the challenge inherent to sharing mortal time: "sometimes you just don't want to do this…have this conversation…the sadness, you know, it's such a difficult thing to do. You know the impact you're going to bring into someone's life, so it's hard to basically psyche yourself up to do that" (E887).

Though these nurses noted how challenging it was to enter into mortal time with someone, they all incorporated that into their practice, and could articulate the *positive* aspects about those complex dimensions of transition to end-of-life care. As they thought retrospectively about their time in cancer nursing, they identified that they had needed to grow in expertise and confidence. Katie shared the story of her first experience with death and how, because of the sensitivity of an instructor, she had learned that she wanted to know how to be a nurse—an exemplary nurse—in that kind of situation (K237). That recognized need for developing expertise is central to the next category.

6.2. *Reflexivity: Developing expertise and challenging assumptions*

Much of Theme B1, "*Doing the right thing right,*" is linked intricately as an antecedent with the development of expertise in transitional cancer care. Dawn referred to having an "intuitive sense" and "picking up on cues" as she entered into difficult discussions, using contemplative responses to parse out the answers to hard questions. For example, she noted that when an ILWPC posed the question, "How much time do I have?", she commented: "I think you have to be very careful about clarifying what they're asking in that question" (D1197). On another occasion she noted that there were some differences in family opinions, and as she was listening to them she was also thinking to herself: "'We're going to have some big issues here, what does this mean?' A lot of it is intuitive and knowing process—[that is,] that people go through that" (D1302). Jane and Sarah's exemplars were also replete with instances of introspection and references to improvements in their practice resulting from that contemplation (Theme B1, FG2J731, FG2S988). Participant nurses spoke reflectively about how they now do things that they would not have done as newer nurses in the field (e.g. FG2S655; FG2J707; D1314).

Learning to challenge personal and professional assumptions was an important element of that progressive development of practice. In so doing they were learning to give ILWPC and their family the permission to have authorship of their own stories rather than "writing" a script for them according to the nurses' assumptions of what might be "best" or "typical." As nurses who were gaining expertise and discernment, they had become more willing to broach mortal time, knowing well the potential attendant challenges and/or privileges. Jane's exemplar in Theme B1 illustrated her learning the lesson of listening to, then trusting the judgment of ILWPC and their family in the personal knowledge of their own "bigger picture" or history. Jane had learned more about not imposing her own—and peer—expectations onto patients' and families' responses and decision-making regarding issues of treatment, a "needed" DNR directive or letter of anticipated death in the face of certain mortality, or other matters of importance (FG2J707). She was not alone (FG2S793; J844; Kr963; M498).

Numerous times nurses made mention of how their practice had changed because of their experience, by what they had learned from patients and families, and from each other, and by how they were more confident to go to team members and ask for input. They were open about differences between professional lenses on care, and were no longer intimidated by having to "tow a particular line" if they knew intuitively, and/or by knowledgeable experience, that certain approaches would likely not work as effectively as others. This combined intuitive knowledge was often based on their awareness of all of the contextual factors they felt had to be brought to a particular situation. In some cases learning from experience meant being more direct or taking initiative to "go there" with ILWPC (e.g., rather than waiting for physician initiation of end-of-life discussion or introducing palliative care as an option (D1123)). Katie described the kind of situation in which she asks "quite blatantly" when there are signs of mental and spiritual fatigue as well as physical, if patients have "had enough" of treatment (K789). She reported that she usually gets one of two kinds of responses: "'Yes, I'm really questioning as to whether or not I want to keep doing this;' or, 'yes, I have [had enough], but I'm going to keep doing it.' It's that little glimmer of hope that people think 'what if something *could* work and I don't do it?'"(K799).

In addition to being more willing to be direct, Katie indicated her experiences had brought about an increased willingness to be open to possibilities, the "gray" areas of care that are neither simple nor straight forward. She provided a story of a couple who knew that the husband was not going to be cured, but together they were going "along with the hope that something miraculous might happen. So why wouldn't I try?" (K765). Her question is demonstrative of reflexivity and underscores the willingness to risk alongside another individual, a risk-taking and vulnerability that conveys a certain maturity and confidence that an inexperienced nurse is generally not willing to venture. Katie's question had been made in the context of a trusting relationship. She noted how she has learned to be respectful of choices when individuals seem to be covering all the bases, to "grab onto something"; "things don't look good (emphasis), but I would only say something to that if he ever brought it up" (K531). Sensitivity to where the ILWPC is in his or her experience was another attribute of these expert nurses. Mary's stories, with similar lessons learned about leaving her own agenda behind and really paying attention to where patients are in their understanding and acceptance, have also already been mentioned (e.g., Themes A3 and B1, M410). Her insightful comment about the story not being ours to write is a powerful observation (M498) and carries with it the mark of learned expertise.

Struggling with the perceived injustices of life is another interconnection between Theme B1 and Theme B2. One can see how working through myriad losses felt vicariously with patients and for their families, as well as personal accumulative grief for loss of life, demands a safeguarding of one's own health. The next category describes this outcome of dealing with living in mortal time.

6.3. *Acknowledging moral distress and accumulative grief, and seeking balance*

There were comments among nurses that reflected some of the deeper impact that vicarious living with death—that frequent experience of sharing of "mortal time" and the resulting accumulative grief—had on nurses in cancer care. Sometimes the cost of sharing mortal time is high. The emotional toll is unrelenting.

Jenna shared the story of an elderly man whose sons had abandoned him; when she called them to let them know how close he was to dying, at home alone, they still did not come. She and a home care worker were the only ones there to come alongside him in his dying—her thoughts that this had been a privilege were expressed in the comment that she had been "fortunate" to be working the day of his death (J824). She spoke of attending his funeral and feeling sadness that his sons had expressed only anger and resentment, and that they had never come to say goodbye. Perhaps Jenna's sadness was deeper than it appears at first glance (i.e., that she was—perhaps unjustly—projecting her own values that the least the sons could do was to be present at the occasion of their father's death). The possible difficulty of the story of the past relationship of this patient with his sons was not explored in the interview. Given, however, that the memory served as a segue to another story of a woman with eight children who spends her Christmases alone, I suspected that her actual intent in sharing the story of the lonely death of the man with disenfranchised sons, was not one of judgment. Indeed, when asked how she felt in the exposure to such situations, Jenna's voice was tremulous and soft, and tears formed in her eyes as she observed that "We can't judge these families. We have no idea what the family history is, so we have to kind of accept it and do the best [we] can" (J844).

Jenna pointed out a commonly held view among the participants that "time constraints" and "the intensity" in the work further contributed to distress: "you don't always feel like you've been able to complete what you feel you *need* to do …so you carry some of that guilt home" (J959). Dawn admitted that she always felt "very tired" after having discussion about a shift to palliative care goals, and that despite individual circumstances it is "always an *emotional* conversation" (D679).

In the context of reflecting on her feelings, Emma commented about the *privilege* inherent in contributing to the dignity and support of ILWPC, and that being able to treat persons in a way in which "you would want to be treated in the same situation" (E469) provided "a sense of accomplishment" (E465). (Her comments about this aspect of applying the "golden rule" again emphasize the interconnectedness of this category of reflection and maturity with ethical and moral practice (B1.1).) She described her role as often being a "spiritual experience" and that she felt "honoured" to have been involved in that part of life with another individual (E478, 484). Indeed, she later referred to such growth affecting her own personal sense of spiritual maturity. She stated her belief that nursing involved more than the "physically healing things that we do; but they can be emotionally and spiritually healing things [too]….My life has changed dramatically since I became an oncology nurse" (E524). Inclusion of a description of the cost of that privilege and the need for reflection followed, however:

> There are lots of times that you come out and sit down at your desk and cry your eyes out…. You should see the group of us! There's probably not enough kleenex to go around some days (*punctuated by a laugh*). I have a wonderful clerk who sits right beside me, and asks for kleenex…. You need a little quiet time to just absorb what's taken place, because this is a life-altering event for somebody. You just helped them make this huge leap and change in focus of their life, their care. You need a little time to digest that. It doesn't always happen at the work place, you know, often it'll happen later, or on the drive home I'll try and sort through that. You need time. You need time (E492).

Thus, it was evident that time for personal reflection was both needed and valued. In fact, lack of time for debriefing and sharing experiences with one another as a source of both learning and support was noted as a significant barrier to self-care (J1104, J1123), and was seen by Jenna as a contributing factor to nurses leaving the field of cancer care (J1108). (It was significant for me to learn, in the "off tape" part of their interviews, that two nurses were seeking employment in another field of nursing. After some time in the area they felt the need to change their focus and locale in order to experience a different dimension to both nursing and life.)

Personal questioning while reflecting was also voiced by nurses. Dawn described her practice of reflexivity: "After every conversation I have with a family member I sit back and say, 'Okay, how could I have done that better?' (*laughs*), you know? What *should* I have said? What shouldn't I have said?'" (D1338). In the focus group, there was discussion about whether or not nurses should take the lead or wait to respond to patient cues of readiness. Jane made the following comments about "getting it right," about struggling with the issue, and about needing to take a risk: "There is always the chance that you…that I, may not have read it quite right. Or maybe I'm going to let that real opportunity go by when I might have been able to do something to make a better transition for that woman in her death" (FG2J690). Her use of introspection and reflexivity to help process those events as well as to draw broader conclusions—or at least questions—about "best practice" was clear. Another dimension of personal contemplation was expressed by Kristen: "Sometimes I come home and say, 'I hate cancer! I don't know why I do what I do.' But I try not to dwell on it. And, I try to live my life to its fullest. That's probably how I've survived for 16 years doing what I've been doing" (Kr1258).

That willingness to focus on other aspects of living and to guard time for family and personal life was noted by many of the participants (e.g., J292, J934, J1104, J1122; Kr1239, M1108). Such attempts at self-care demonstrate self-awareness and a significant aspect of coping. It takes time and skill for nurses to learn the lessons and importance of seeking balance and setting appropriate boundaries for their own personhood. Nurses' responses to the interview question about how they would mentor a less experienced nurse, or someone new to cancer care, focused attention on the issue of self-care (e.g., J946, K1182). (Mentoring will be discussed further in category B2.4.) Jenna indicated that sometimes nurses "don't give ourselves permission to look after ourselves. We're supposed to be on-call for everybody else all the time. That *permission* is important" (J946).

Nurses acknowledged that they often shed tears (e.g., D1043; E492; J713; K1229; Kr722; M505) or felt the burden of sadness (e.g., E450; J838; Kr722). In the context of remembering a patient story that evoked tears, Mary reflected that "I think you carry these stories with you wherever you go" (M468). The need for some sense of closure, of pausing to respect and celebrate an individual's life and a relationship that had affected the personhood of the nurse, of saying "good-bye" to patients and families, came up frequently, too. Given that many nurse-patient relationships have been sustained over a period of years, as well as months, acknowledgement of grief is probably a significant antecedent to being freed to be there with an openness to *new* stories, to care for new people in new relationships.

Stories of the significance of "presencing" with persons for whom they had cared, and who were now dying, were a few among many of the very moving recountings of nurses' involvement with patients that were shared (e.g., FG2J1047; FG2S1075; FG2V1168; FG2R1212). Taking opportunities to say goodbye, of completing the unfinished work of grieving was done sometimes on the nurses' personal time outside regular hours of work. Rather than that being a sign of imbalance, it was spoken about in a way that experience and knowing personal boundaries shaped the nurse's own personal awareness of self. For some there were times when the extra effort—or risk of stepping outside accepted routines or expectations—was worth taking because living with regret or having missed opportunities to say good-bye actually increased the burden of moral distress. Rachel stated it this way:

> If there's ever a feeling of inadequacy and work not done, it's not saying goodbye properly to my patients.... I think back to experiences when I was younger and I didn't know *how* to do that, or that it was okay to do that. The frustration was because I was in charge of other patients. I felt I had other *things* that I was paid to do—not sit there. But I learned from another nurse (*voice wavering and emotional*) who had the insight and courage to say 'I'm sitting with this patient' because he was dying. I admired her so much for doing that. I supported her as one of the nurses working with me (she happened to be an LPN), because she knew this patient was not going to leave this world alone. For me it was probably an out, that somebody else was going to sit there, 'cause if it had been important to me I would perhaps have done that, right? For me, I thought that it was *wonderful* that [she would] *say* to me 'I'm not doing the rest of this stuff that doesn't matter right now.' I just so admired her for that. So a lot of unsaid good-byes... (*voice wistfully emotional*) (FG2R1212).

Yet all the nurses balanced such comments about the *cost* of mortal time encounters with observations about the joys and benefits, too. In addition to the sense of satisfaction, accomplishment, and spiritual growth, benefits that were cited earlier in this section, nurses also emphasized that while there was sharing of tears and grief in their work, they laughed together a lot, too (Kr1282). Even during the course of the interviews there *were* many times when laughter was used by the respondent-informants to lighten emotionally "heavy" parts of sharing stories and observations (e.g., D715; E497; J437; K493, K622, K1231; M307, M524, M971, M1139; Sp437; FG2S816). Other reflections were provided by the participant nurses, expressing their feelings as they sought to maintain perspective and to seek healing within the context of persistent grief. Sarah revealed her viewpoint in the following excerpt:

> I have been the second person to touch a newborn baby and the last person to touch a person who has died. And they are *equally* as *moving*...a privilege for me as a nurse to experience something so personal with this other human being or family.... That's probably what has kept me in nursing as long as I have been in nursing (FG2S463).

In spite of acknowledged exposure to the rawness of death and dying, Mary identified several life lessons gleaned from the rich experiences of living in mortal time with ILWPC. These lessons included: learning to make the best of each day, teaching her husband to be more carefree with money (another time of laughter); learning spiritual lessons along with patients (and of having them teach her); valuing family; pursuing personal dreams *now* rather than procrastinating until later in life; and, letting go of "sweating the small stuff" (M1026). In the context of "lessons learned," Mary shared a story from her experience with a young adolescent who was not going to survive his cancer and treatment with bone marrow transplant. Thinking he was asleep, his mother commented that she wished she had never put him through the treatment. Mary described the amazement of herself, as well as his Mom, as he responded: "well it wasn't your decision, now, was it Mom…I would have gone through this again even knowing what I know now" (M1171). This story was provided to support her observation that "sometimes you learn things from the most unexpected people—people that you think are too young, or too whatever" (M1139). Interestingly, the lesson Mary learned from this young boy was echoed in her stories of other ILWPC in which she acknowledged respect for their autonomy even when she herself might have made a different decision (M340, M498). Others had noted their desire to better understand how some individuals came to a point of peace, even acceptance of their mortality (e.g., K149, K886; FG2S1013) while acknowledging that many individuals for whom they were caring did not ever appear to come to that place (e.g., K147; Sp599; FG2S815; FG2V927). The need to continue to learn from one another—even from unexpected places and stories—as well as to mentor others is a salient attribute of the next and final category, that of "creating spaces for new stories."

6.4. Creating spaces for new stories

The questions that led me to this research were affirmed by the participants at numerous points in the process. One of the deepest concerns that urged me to ask the questions was a felt need to discover more about how we can mentor nurses newer to working in this complex time in peoples' illness trajectory. One of the expert nurse volunteers for the focus group came back to my question about mentoring. Her interest in exploring the question follows: "How we can do that [mentoring] better, because it feels like a lot of the time we are doing that [learning] on our own, that it's by trial and error and by our experience. As a nurse administrator, how can I create the space for that to happen so it's not as much of a struggle for people…for nurses?" (FG2J1379). Non-verbal as well as verbal affirmation of the importance of the question was expressed by the group. Initial responses identified that they had learned the "hard way," that is, through experience or "trial and error" (FG2S1395) and independent learning. Rachel reminded the group that her story of peer example (i.e., the LPN's rejection of routine in order to sit with a dying individual) was another method of learning that "drove that one home" for her (FG2R1420). Jane raised the problem that though there was "informal discussion that goes on," role-modeling had its limitations because so much of "the work is unobserved" (FG2J1430).

The concern was expressed again as a question of how the learning could be facilitated so that a desired outcome of greater peer understanding, sensitivity and flexibility for "presencing" could be accomplished. In addition to respect for the lessons learned from patients as noted above, spending time with new nurses and encouraging them to reflect on their own values, beliefs and feelings about caring for ILWPC so that they are self-aware was a significant part of teaching peers (J913, K1181). Allowing time, probing and using reflexivity to encourage self-awareness, as well as acknowledging the need for self-*care*, were dimensions of mentoring that some nurses expressed wishing had been a part of their orientation. They suggested that the focus of learning had to be not just on tasks, but on the broader and deeper issues that enter into the nurse-patient relationship (J923, K1196). Role modeling, or "learning by example," coupled with the need to "give them time," were identified as significant to mentoring. But a most consistent answer to the question of how to mentor less experienced nurses came in the form of, and desire for, storying and the reflection that those stories evoked (e.g., D1389; J1002; Kr1213; K1237; M795).

The therapeutic effects of sharing stories were noted by a number of nurses. They saw them as a personal means for debriefing, or "cleansing" (K1272), or working through grief (J1112). They were used in decision-making, especially as they grappled with difficult choices and their motive to do the right thing right. They were also used as an evaluation tool as nurses talked together about how they handled a given situation (e.g., D1391). Peer understanding, affirmation and feeling as though someone who can understand has been there were other benefits noted (J814, J1116). At the conclusion of the focus groups the participants all indicated how meaningful the experience of the focus group itself had been to them. One commented that she could "just keep on going, although I'm tired now" (FG2R1502). The same kind of observation had come from the individual interviewees as they noted the therapeutic effect the time for reflection and sharing of their stories had had for them (e.g., D1385; Kr1503). These kinds of comments seemed to further validate the significance of the beneficial effect of reflecting on nurse-patient interactions.

And finally, the importance of facilitating the space for creation of new life chapters in the narratives of patients was identified as having done the right thing, and of feeling a sense of personal gratification as a nurse in transitional cancer care. "I certainly know that empowering patients has been extremely rewarding for me" (K612).

Conclusion

The findings of this study confirm the complexity of issues which nurses face as they journey into mortal time with ILWPC. There are no quick and tidy maps to provide specific direction to new nurses in transitional cancer care. However, the findings underscore the necessity to be still, to presence with others and listen to the voices and stories of ILWPC and their families, so that their particular values, social contexts, and challenges can be better understood.

Enhanced understanding of a greater portion of the individual's story—not just their health history—enables experienced nurses to discern with wisdom and sensitivity where the person is in their readiness to transition. Coming alongside, preparing the way for ongoing transition and readiness for palliative treatment options, providing the necessary teaching and care coordination are all tools that the nurse provides to enhance autonomous decision making. At the heart of this caring is the desire to do the right thing and to do it in a respectful manner—a manner that embraces and integrates the values of the CNA code of ethics. The vulnerability in entering mortal time is in actuality a strength, for it causes cancer care nurses to be cautious, to check out personal and professional assumptions, and to be ever aware that we do not have all the answers. Nor do nurses—even given their rich experiences and maturity in the profession—have the authority or right to assume authorship of another person's story. Mature nurses recognize that getting patients to accept their mortality may not be the desired goal of care, but rather that enabling a respectful journey that is dignity-enhancing is the desired outcome of nursing intervention and caring.

Acknowledging the costs as well as privileges of the nursing role is a part of the reflective and reflexive thinking that shapes the strength and sensitivity of each nurse as she or he continues to attend to accumulative grief and the demand for balancing personal and professional life. Such self-care and self-awareness are integral to the role of mentoring others, and the powerful influence of sharing stories cannot be minimized; indeed, the use of narrative ought to be explored and researched further as a teaching and healing medium.

CHAPTER FIVE

SHARING MORTAL TIME: INTERPRETATION OF THE FINDINGS

Introduction

The findings of this study are further discussed in this chapter in light of the statement of the problem, the literature review, and the conceptual frameworks guiding the study. Limitations related to the methodological design and sample, noted in Chapter Three, are further touched on. Recommendations linked to the relevance of the findings for nursing practice, education, administration and research are identified and some general conclusions delineated. The effect of the process of the research on the researcher is woven into the discussion as reflections and thoughts about reflexivity in the researcher role.

Relationship of the findings to the literature, the conceptual framework and the research design

The focus of investigation was the exploration of how expert nurses discern patient and family readiness to discuss issues of concern in the transition from curative care goals to palliative care; and how nurses describe relevant aspects of their role in the experience of turning towards death together with ILWPC. Exploration of these dimensions of practice were framed by the following areas of questioning:

- discernment of patient readiness to deal with talk that reflects patient awareness of their death
- descriptions of barriers or constraints experienced in broaching palliative care

issues

- narrative descriptions of mortal time experiences of nurses as they cared for ILWPC, persons and families in transition, with explication of what factors they thought were influencing outcomes of times when transition to palliative care did—or did not—go “well”
- descriptions of self-preparation and thoughts about the nurses’ own moral agency in the interaction with the ILWPC and/or his or her family
- exploration of approaches to mentoring newer members to cancer nursing, especially in relation to transitional care
- exploration of reflective and reflexive practice regarding personal stories of sharing mortal time as witnesses, with attention to nurses’ experiences of dealing with the impact of the work and self care practices.

Many health care practitioners in cancer care believe that timeliness of supportive intervention, including referral to palliative care supports, contributes to optimal quality of life as individuals live with the paradoxical knowledge of their dying (e.g., Davies & Oberle, 1990; Dudgeon, Raubertas, Doerner, Connor, Tobin, Rosenthal, 1995; Gould, 2003; Howell, Fitch & Deane, 2003; Jeffrey, 1995; Lo, Quill & Tuskey, 1999; Lowden, 1998; Lynn, Schall, Milne, Nolan & Kabcenell, 2000; Massarotto, 2000; Norton & Bowers, 2001; Ronaldson & Devery, 2001; Strauch, 2003). The nurse participants in this study are no exception to this view. The literature review of Chapter Two demonstrated, however, that while timely discussion and supportive intervention is upheld as a desirable outcome, the challenge for care providers in translating their belief into practice is fraught with the complexities of human behaviour during life transition and entry into “mortal time." The concept of "mortal time" was described thoroughly by McQuellon and Cowan (2000) and summarized in Chapter One. It was a concept that captured some of the essence of the relational space between nurses and the persons for whom they care. The concept was intricately linked with the data and the discoveries of analysis as the emergent themes described in Chapter Four revealed.

Numerous authors have identified the importance of certain behaviours in nursing care of the dying (e.g., Curtin, 1996; Davies & Oberle, 1990; Donovan, 1997; Kristjanson, McPhee, Pickstock, Wilson, Oldham, Martin, 2001; Lynn & McMillen, 1999; Perry, 1998; Radwin & Alster, 1999). Common to much of the literature was a focus on the need for communication skills that are key to assisting ILWPC disclose their concerns. Others suggested strategies to enhance care provider sensitivity to truly hearing what patients and families have been saying—through their words, silences or other behaviours—when they are *ready* to share (e.g., Baile & Beale, 2001; Booth, Maguire & Hillier, 1999; Bowman, 2000; Craven, 2000; Buckman, 1992; 1988; Maguire, Booth, Elliot & Jones, 1996; Maguire, 1999; Maguire & Faulkner, 1988, 1993; McGrath, Yates, Clinton & Hart, 1999; Ptacek & Eberhardt, 1996; Thorne, 1988). The desired outcomes of skilled communication seemed to be embodied in many of the exemplars of the nurse participants of this study, strengths of expertise that confirmed the veracity of the findings.

The findings in relation to other research studies

Attributes of the themes and categories that emerged from the data of this study fared comparably with the findings of similar studies as reported in the literature (see

Table 1, Chapter Two, p. 57-58). For example, the concept of acknowledging the unique personhood of individuals (Theme A1) in a therapeutic relationship with a health care provider was emphasized by Davies and Oberle (1990). Concepts of processing and facilitating transition, along with the inherent elements of timing and decision making, were acknowledged in all four of the highlighted studies, in a variety of ways. In yet another study, McGrath, Yates, Clinton and Hart (1999) identified the importance of "finding the right occasion and opportunity to talk" (p.27), a finding echoed in the comments from the nurse participants in this study, and embellished as noted in Theme A1 ("connecting," and "being with while doing for"), Theme A2.2 "reading readiness cues" and "feeling your way"), and Theme A3 ("opening the door and using opportunities"). The unique attributes for each of the categories were thoroughly explicated in Chapter Four.

Norton and Bowers (2001) seemed to encourage responsibility for health care providers to "shift" the patient and family decision to one which was deemed more "realistic" and reflective of the "big picture," while this study and that of Ronaldson and Devery (2001) emphasized the need to be responsive to the readiness of *patients*. The importance of *knowing* persons in care was emphasized by the nurse experts in this study and is an aspect of nursing well documented in the literature (e.g., Luker, Austin, Caress, & Hallett, 2000; May, 1993,1995: Rogers, Karlsen, & Addington-Hall, 2000, Parker, 1990; Tanner, Benner, Chelsea & Gordon, 1993). While there is acknowledgement that experience *sensitizes* health care providers to know "best" according to all the clinical indicators of the advancing illness, the expert nurses pointed out that even in areas where up-front teaching and preparation for such issues is *routinely* incorporated into care because it has been deemed to be the "best" approach, there may still not be *readiness* on the part of the *patient* to hear it. Jane's story of the couple who had delayed decisions about resuscitation in the context of their personal history of surviving the holocaust was a poignant narrative—a reminder to health care providers that our professional assumptions may need to be challenged.

Findings of this study also align well with themes from Kelner and Bourgeault (1993) who emphasized that patient control represents a challenge to professionals' clinical judgment. Care planning then has to be responsive to where the ILWPC *is* in their story, rather than trying to pressure persons into certain decision making because nurses or the care team feel *now* is the appropriate time, or that a particular outcome (e.g., registration with a palliative care program) is the "best" or most "realistic" option.

Similar to expressions by nurses in this study, palliative care nurse participants in the study by McGrath, Yates, Clinton and Hart (1999) confirmed the potential for discomfort and distress in nurse-patient relationships resulting from tensions over treatment goal setting and the timing of talk that acknowledges mortal time. Their study described "resistance to talk," associated with denial and optimism, as a block to communication. This project expands on other reasons for resistance such as resignation to illness progression, leaving a legacy of "a willingness to try everything," or a misunderstanding of the use or ascribed meanings of language.

Davies and Oberle (1990) identified empowerment of individuals as significant, a care strategy comparable to Themes A3 and A4 ("Preparing for mortal time," and "Processing and facilitating transition with the ILWPC"). The subtle difference between the studies was that in this study there seemed to be a greater emphasis on *shared* responsibility between ILWPC and the nurse, rather than the nurse usurping the intrinsic resources of the patient and family by assuming a "doing for" stance that may convey unwelcomed control. Perhaps the invitation to greater patient autonomy is reflective of a general perspective that has been evolving over the last decade since their study was done (e.g., Degner & Sloan, 1992; Degner, Kristjanson, Bowman, Sloan, Carriere, O'Neil, Bilodeau, Watson, Mueller, 1997).

Kelner and Bourgeault (2001) emphasized the dynamics of professional differences in their perceptions of power and control when considering patient autonomy, noting that nurses in their study were more "comfortable" with team or shared responsibility than physicians, a dynamic both supported *and* refuted in this study, depending on the participants' team membership and their particular pattern of functioning. Much of the tone for that functional pattern was set by the physician, or group of physicians with—or 'for'—whom the nurse worked. The behavioural attitudes, expectations, communication patterns and interrelationships of team members, particularly that of physician-nurse dyads but also with nursing peers, was an area of work described in the findings that either enhanced or created barriers to effective transition for ILWPC.

Relationship of the nursing role in transitional cancer care to the conceptual frameworks

Explanatory models

Believing in the veracity of Meleis' (1997) injunction that nurses' use of an integrated "biopsychosociocultural" perspective of transitional phenomena in their interactions with people (p. 109) led to the choice of Arthur Kleinman's (1980, 1992) theory of explanatory models (EMs) as the primary theoretical framework used in this study (Chapter Two). Kleinman contends that people use explanations for individual behaviors based on the intersubjective reality of both their single and social realities. The theory was supported by the findings in that the nurses' explanations for how they assess readiness behaviours in ILWPC reflected the need to connect the cognitive clinical parameters of disease progression with patients' understanding of that information, as well as their feelings of uncertainty, shock, denial, distress, anger and other emotions characteristic of the transition to palliative care.

Processes involved making sense of things, such as language. Dawn's reference (Chapter 4, A2.4, D386), for instance, to the story of the woman who had taken offense at the word "terminal" confirms other studies (Payne et al, 2002; Friedrichsen, Strang, & Carlsson, 2002) which emphasize the need for health care providers to understand the significance of words when providing information to patients. An analysis of truthtelling issues in palliative care (Fallowfield, Jenkins, & Beveridge, 2002) is supported by the findings in this study as highlighted by Sarah's exemplar in which she described the disastrous outcome of a physician having used ambiguous language in an attempt to protect the patient who needed a stent inserted as a result of tumor growth. (I found her description of the patient's shock as he realized the truth of his cancer progression—something he had not clearly understood because of the words that had been used to convey the progression—emotionally moving.)

EMs of key informants such as Sarah and the other nurse participants were helpful in better understanding the flow of interpersonal relationships that affect care provision. (Sarah, for example, had pointed out that at times she explained the philosophy and option for palliative care “in-the-closet” in order to get around the reluctance of a particular physician to do so with patients.)

Heeding Kleinman’s advice to avoid superficial descriptions, explanations of transitional cancer care were sought through the research design of combining person-centered interviewing—with its strong focus on contextual factors—and with focus group interaction. The use of researcher observations about the contextual channels of non-verbal communication factors, as well as verbal, were also used in this study as a contribution to descriptive depth.

Kleinman (1992) also encouraged appreciation of the local context’s political, economic, institutional, relational and cultural patterns in their application to health care issues (p.133), and these influencing factors have been given attention in the four preceding chapters. At the time of access to the institution and the introduction to potential nurse participants, several salient external and internal factors may have influenced nurses’ decisions about participation, including: reverberations of September 9, 2001, with the events of terrorism highlighting both vunerability and strengths of individual persons, and a need to attend to family; a threatened work stoppage; increasing workload intensity (many overtime hours incurred by both care needs of patients and issues surrounding the information technology of the patient health record in the cancer care network); care delivery systems changes within and without the organization adding inherent stresses linked with the processes of change; and, finally, acknowledgement of the nature of work that is intrinsically emotionally and energy demanding.

It is equally significant, however, that there were nurses who felt drawn to participate, and that they would have sympathized with the participants in May’s (1995) study who said "to call it work somehow demeans it" (p.560). (See especially Themes B1 and B2, but also in categories such as "weeping with" (A1.2, Theme A1), and the contextual factors, (A2.3, Theme A2) described thoroughly in Chapter Four.)

Other factors influenced the nurses' EMs as they described their roles in transitional cancer care. In the organization from which the participants were being sought, there had been major construction as well as renovations taking place in the two sites where the nurses worked. It had been a stressful time of adaptation to a disruptive environment in which to provide care. Sarah's story of her poignant interaction in a corner of a "waiting room" hallway with a gentleman who was just beginning to realize the full impact of his illness progression, was one example of this space barrier to effective care (FG2S293, A2.4-A3.1, Chapter Four). Regional restructuring of the health authority's palliative care services was also concurrently going on, resulting in increasing access to pain and symptom management under the heading of "supportive" cancer care, new physician and clinical nurse specialist positions for palliative care management, and redefinition of the criteria for access to palliative care services. Many of these factors enabled improved palliative care, were significant to transitional care and the EMs of the nurse participants, and thus to the data. The criteria have placed greater demand on clarity of communication that is discerning, for while patients are receiving chemotherapy that is palliative in its intent, they are not able to access the palliative care program per se. This has potential for added confusion surrounding the broader meaning of "palliative care," especially given that palliative radiation does not preclude enrolment on the palliative care program.

Understanding EMs of either illness or care can serve as a basis for negotiating therapeutic interventions; and, understanding the *differences* between EMs of lay persons and their health professionals may diminish potential communication issues and lead to improved knowledge, understanding and health outcomes (e.g., Ahlqvist & Wirfalt, 2000; Alcozer, 2000; Facione & Katapodi, 2000; Mahoney & Engebretson, 2000; Reifsnider, Allan & Percy, 2000; Russell, Geraci, Hooper, Shull & Gregory, 1998; Sarvimaki & Stenbock-Hult, 2000). This basis for improved knowledge was the underlying goal of this research study. The findings have provided further understanding of what happens in nurse-patient relationships in the inherent complexities of transitional cancer care. Knowing the patient and the context of each person's story was identified by the nurses as a way of challenging assumptions and creating a common ground for the expectations of care. Jenna, for example, had felt confused by a gentleman's refusal of radiotherapy as a palliative intervention for spinal cord compression. Once she listened to his explanation of his spiritual values and interpretation of these events, and once she felt secure that his decision had been an informed one, there was at least a common understanding of his refusal. This was characteristic of a number of the nurse participant narratives. Thus, even though nurses did not fully accept or understand certain rationale offered by patients, nurses accepted and respected autonomous decision-making that was based on the patients' culture, personal values and narratives. A variety of categories in Chapter Four provide examples of mutual communication between patients, families and nurses and other care providers working to understand the differences of their explanatory models in order to diminish misunderstandings and set common goals for care.

Transition theory

The second conceptual framework that was incorporated into the process of the research was that of transitional theory. The basic tenets of combined theories of transition are that transitions are processes that occur over time, involve movement from one state to another, and that both change and internal processes are involved (Bridges, 1980; Davies, Reimer & Martens, 1990; Schlossberg, Waters & Goodman, 1995; Schumacher & Meleis,1994). The findings of this study confirmed the aggregate tenets of transition as a conceptual framework, while offering added dimensions to the depiction of the experience.

One nurse had included a description of transition that initially caught me off guard because, contrary to much of the literature, she had offered a description using words such as "it's like a gentle shift from being acutely aggressive, like active aggressive treatment into the more supportive therapy, and it's a period of time where roles are changing" (E288). After noting how difficult it was to describe transition she also added that sometimes it could be "very harsh" and that it wasn't "clear cut" (E309). Integrating her perspective of transition having gentle aspects led me back to Bridges' (1980) term of the "neutral zone" which had also stood in contrast to the shock, chaos, and uncertainty described by other participants, and in the literature (e.g., "existential plight" in Weisman and Worden, 1976). Thus, reminders of the quieter aspects to transition are noted on the right area of Appendix B, behaviours such as reflection, sadness, and acceptance, which may lead into the area of new beginnings or "reinvented self" (Tefs, 2002).

The overlay of nurses' experiences with *each* ILWPC and that persons' social family, represented one of a matrix of *concurrent* and unique experiences. It seemed that transition in cancer care was less "tidy" or succinct than most models proposed in the literature (e.g., Bridges, 1980; Davies, Reimer & Martens, 1990; Schlossberg, Waters & Goodman, 1995; Schumacher & Meleis, 1994). Perhaps based initially on my own clinical experience and observations, and then confirmed by the emerging findings and the second Focus Group participant discussion, I felt I better understood why those models had seemed inadequate.

As I tried to articulate these thoughts about the matrix of transitional cancer care in meetings with my advisor, and with a close friend who has gone this journey with me, their questioning and probing helped me to clarify certain dimensions of the phenomenon. Reflection and reflexivity were important to the process, and I continued to gain further insight while going back—again and again—to the original transcripts for inspiration and confirmation.

Reading interpretively stacks of related literature to better understand some of the phenomena associated with the findings and processing the research continues to inspire my thinking. That joy alone has made this personal journey privileged and worthwhile. For instance, though I had deep appreciation for Davies, Reimer, & Martens' study (1990) and then book, Fading away: the experience of transition in families with terminal illness (Davies, Reimer, Brown & Martens, 1995), I found myself troubled by the core theme and title. Explanations for the concept of "fading away" indicated that the influence of changing physiological status—a waning of ability—inhibits "the expression of other aspects of the person" (p.3). It seemed from the narratives of the expert nurses in this study that some ILWPC had become heroic in some measure *despite* advancing disease and its incumbent physical deterioration. I had to challenge my own assumptions, too, as I recalled the stories of the participant nurses: Jane's of the family who had lived through the holocaust; Jenna's of the patient who expressed concern for her as the nurse because she was troubled by his decision to live with an impending spinal cord compression rather than complete a course of recommended radiotherapy; Katie's, Emma's, Dawn's, Spencer's and Sarah's stories of persons seeking treatment and not giving up "the fight"; Mary's stories regarding the young man who so remarkably called on the strength of his faith and accepted with equanimity news of his progression when he saw his CT scan, and of the woman who chose, in spite of her own fear and uncertainty, to go through bone marrow transplant so her husband's grief would not be fettered with wondering if they "had done everything." These true life narratives were hardly reminiscent of "fading away" behaviours.

Hence the rendition of Appendix B in attempt to demonstrate the untidy jumble of reactions in transition. How does one describe the *layers* of impact being experienced by nurses caring for many ILWPC at differing stages of transition? Nurses were continually having to parse out the significant factors of each individual story, being sensitive to the patient's readiness for broaching issues of mortal time, while coping as nurses with their own responses to each story as well as the collective impact of the suffering of many others. The magnitude of their role came to me in fresh ways as I "dwelt with the data." The profundity of that shared experience of mortal time—the nurse as witness and sojourner, the patient as owner—led me to further attempts to depict the relationship and work of cancer care nurses with patients as noted in Appendix M. Despite adding the multiple "rings" of care dimensions that emerged from the findings, the combined multiplicity of emotion, rational thought processes and relational matrices still remains inadequately illustrated as offered, however. This researcher extends the challenge to other nurse researchers to continue attempting to learn more about this multifaceted area of care. The profession needs to seek better ways in which to describe the model of nursing care for persons living with either progressing cancer or perhaps other chronic illness trajectories that create shared mortal time experiences.

Expert practice

The theoretical framework of nurse expert behaviours as explicated in Chapter One was also woven into the research study and is discussed more thoroughly under "sample attributes" in the next section.

Relationship of the research design to the findings

The birth of the study question occurred to me in the context of a clinical situation. As nurse manager of an active outpatient cancer clinic whose role also included the development of palliative care services in a community hospital, I was involved in complex family conferences as ILWPC and their families were transitioning to palliative care. Having requested a learning opportunity a nurse accompanied me to a family conference. Afterwards she asked how I knew "how to go there" at a point in the conversation which had led to greater openness and disclosure by the patient about her concerns—matters that she had not even shared with family members. The nurse's question gave me serious pause as I tried to reconstruct what seemed to be intuitive in the interaction we had experienced together with this family. I realized how important her question was to cancer nursing practice and education, and to the possibilities for nursing research of a sensitive, value-laden and complex issue. For me these interactions were never "easy" in the sense that there were moral and ethical considerations that constrained me from "rushing in" without a certain level of angst. The questions of "How?", When?", "Why?" and "What?" to say were brought into sharper focus as I reflected on my nursing practice and leadership. I felt compelled to satisfy her curiosity and critical thinking—not just for the two of us—but for other nurses in cancer care who were living these questions on a regular basis.

The decision to use an exploratory, descriptive qualitative approach to discover more fully the nature of the relationship between expert nurses and ILWPC—including the social family and other care provider relationships—in the outpatient cancer care setting was deemed fruitful as well as appropriate.

Sample attributes: a discussion of the role of cancer care nurses' participation in sharing mortal time

Response rates for the peer-nominated interviewees has been discussed already in Chapter Three, under *Sample attributes*. Overall, the response rate for the peer-nominated and voluntary "experts" was gratifying. Though the small size of the sample was identified in Chapter Three as a limitation, the tensile strength of the data provided cannot be dismissed. Participation in the study may reflect a link with motivation and typically reflective practice. In the "ice-breaker" questions at the beginning of the interviews I had asked the participants what led them to volunteer. All the nurses expressed feeling this research project was an important issue for them, that transitional cancer care was challenging, that they faced the issues on a regular basis with ILWPC, and that they wanted to assist in the articulation of the nursing role and reflect more on patient receptivity to the concept of palliation. One nurse indicated her interest was founded on her strong affinity to palliative care and her curiosity about why it seemed easier for some persons and so difficult for others to transition from curative goals of care to palliation. Some indicated that participation was helping them feel connected with the significance of nursing and the nature of nurse-patient relationships that drew them to nursing in the first place. Others suggested that they had benefited from research and the help of others so now they wanted to give back to the profession and perhaps encourage others to stay in nursing. An expressed desire to be exposed to experiences that would help them grow professionally, and to be a better cancer care nurse because of a deep love for this kind of nursing was another reason that attracted participants.

Such passion for this work was expressed by most of the participant nurses, and I wondered if attributes of commitment and passion had been an antecedent to their development of expertise. Their passion and commitment seemed to be sustaining traits, too, for many of the participants had been in cancer nursing for over 69% of their nursing career (based on the median number of years as a nurse in cancer care (12), and the median number of years as a nurse (17.5)). Given, however, that 50% of the participants fall in the age bracket of 40-49 years, these traits may change, concomitant with the larger picture of professional stays in particular fields of care and whether or not we learn to better support nurses in the ever-expanding practice and duration of chronic cancer care (Cancer Statistics, 2002).

In the matter of expertise, I believe that the attributes that were identified in the literature review ("expert" definition, Chapter One, p.27-29) (e.g., Adams, Duffield, Nagy, Crisp & Mitten-Lewis, 1997; Benner, 1982, 1984; Benner & Wrubel, 1982;

Benner & Tanner, 1987) have been confirmed in the findings. The nurse participants consistently demonstrated responses that reinforced their combined advanced competencies in critical thinking, highly selective assessment skills, and in applying experience, knowledge and intuition to complex contextual circumstances. Their interactions and reflections revealed perspectives that were insightful, holistic and sensitive to the comprehensive picture. There were many examples of transformative emotional and informational support for others. Though there were times when they tried to "unpeel" the layers of contextual factors typical of transitional care, they were able to discern matters in a manner that went beyond following of a particular set of prescriptive guidelines. Their respect for reflexivity as a part of their nursing practice while they reflected on how they themselves influenced whole person care and the unique features of patients' narratives within the bigger picture was distinctive in their practice and participation.

One finding left me concerned. That a few nurses admitted to crying on a regular basis created a paradox for me given their tremendous insight about so many aspects of their professional role. The routinization of suffering and death with resulting objectification of persons and detachment from mortal time events, phenomena observed by Chambliss (1996), did not seem to be borne out by the findings of this study. Nurses in this study *did* notice and care about the impact of progressing illness for people living with that knowledge. On the whole, there was combined tenderness with hardiness and a concern that they be strong for patients and families. Though I was responsive to nurses' reference to their tears in the moment, it was an area that as a novice researcher I felt conflicted about knowing how far to probe. Certainly, the significance struck me forcefully then and a year later still does. When the balance of hardiness is outweighed by a tenderness that is openly wounded there is need to pause. It is an area arising from the findings that begs further attention.

The willingness of participants in this study confirms their strong interest in improving communication, an interest noted elsewhere (e.g., Bakker & Fitch, 1998; Fallowfield, Saul & Gilligan, 2001) and in contrast to the work of others who have demonstrated that nurses and physicians do not always recognize their need for communication skill development (e.g. Parle, Maguire & Heaven, 1997). Yet the lack of nurse volunteers for the first focus group may confirm either ambivalence or lack of awareness of their need to improve communication as noted by Parle and affiliates and others (e.g., Booth, Maguire, Butterworth, & Hillier, 1996; Bowman, 2000; Craven, 2000; Buckman, 1992; McGrath, Yayes, Clinton & Hart, 1999; Ptacek & Eberhardt, 1996; Thorne, 1988) who have noted the need to diminish "blocking" of open communication in cancer settings. While I did not sense from the data offered by the respondent-informant nurses, that such "blocking" behaviours were predominantly characteristic in *their* perceptions of their communication with ILWPC, I did wonder about possible reasons for the hesitancy in others to participate. Speculation may not be helpful, but the loss of the perspective of nurses who were not nominated as "expert" is a loss of comparative richness to the data.

Regardless of the reasons, one may surmise that the sample of nurses in this study had been peer-nominated because they had been regarded by others to have exceptional abilities in this area; that there was enough visibility of their work that they did not avoid opportunities to "plant seeds" or "ease gently" into mortal time conversations with patients and families. Indeed their shared narratives indicated that these expert nurses may have taken leadership roles among team members, and at times prompted attending physicians to consider palliative care when that option was not explicitly being offered to ILWPC. With the exception of one participant who had hesitation about introducing the idea of palliative care because broaching the issue may create risk of harm in the form of dashed hopefulness for patients, the remaining nurses felt that the benefits of earlier referral and providing adequate information outweighed the burden of missing appropriate timing all together. Others would support this view from a nursing and ethical stance (Fallowfield, Jenkins & Beveridge, 2002; Henderson, 2000; Scanlon,1998; & Shotton, 2000).

Does the perception of the informant respondent nurse about other nurses who may feel inadequate or at least uncomfortable to the degree that they leave the responsibility at the door of physicians only, give indication that a large proportion of nurses working in a provincial cancer centre are *not* "going there" (i.e., discussing issues of transitional cancer care such as palliative care, advance directives, relational, financial and spiritual concerns that may need resolution) with ILWPC? With the response to participation in the focus group being disappointing I was left wondering if the topic was too uncomfortable, or if I had not adequately or sensitively enough explained the purpose of the group interview. (See Appendix F). (Participation for Focus Group One had been focused on cancer care nurses at "several levels of clinical practice proficiency," not "expert" nurses. I had explained that "sometimes nurses may want to develop even more expertise with certain aspects of cancer care, and their questions, concerns, insights, and stories can provide valuable probing into the issue itself or about the practice of nurses who are recognized as exemplary in those areas of care." The nurses were to self-select according to the proficiency levels III-IV as described on the form, and "as determined by the nurse's own self-awareness" (Appendix F).)

I have no definitive answers as to whether the small response rate for this portion of the study was because of a lack of clarity about the research goal, or whether nurses were somehow feeling that voluntary, as opposed to peer-nominated participation based on a level of judged expertise was an indicator of lesser valuing of their contribution (something I had hoped to avoid by explaining the value of both groups to the study), or whether there was general angst or discomfort associated with the topic per se. This last possibility might be supported by the literature on communication in cancer care. Parle, Maguire, and Heaven (1997) for instance, point out Bandura's construct that individuals with "strong beliefs in their ability to perform a behaviour successfully are more likely to initiate the behaviour and persist through difficulties, while those with poor self-efficacy will avoid the task" (p.233).

In his comparative study of palliative and curative care nurse attitudes in hospital settings, Thompson (1985) had revealed findings that some nurses who had to provide terminal care in a curative environment were simply unable to therapeutically deal with the dying patients. It appeared that the setting of their work was a more significant influence on shaping attitude than experience. This was of interest in light of the difficulty with recruitment for Focus Group 1 and theoretical sampling that had been sought for this study's methodological design. One might ask if a study similar to Thompson's done in the outpatient cancer setting would provide comparative results where certain teams, especially those strongly influenced by some oncologists, are more comfortable when focused on curative outcomes of care than in dealing with individuals who are more clearly needing palliative intervention. Nurses functioning in such a setting within a cancer care institution may not always have support for a proactive role in spending the necessary time to develop expertise and confidence in broaching palliative care issues with ILWPC. Indeed, Sarah's reference to "in-the-closet" discussion, and Emma's, Jenna's and Dawn's descriptions of their role in initiating "palliative care talk," confirm that premise.

Now that additional support services are available in the organizational setting for this study, there may also be a tendency to refer persons to supportive care consultations rather than to fully respond to them in those "open door" moments of opportunity that were described by the expert nurses. Personal factors related to workload, vulnerability, hesitancy to be reflective about one's practice in a public forum, and lack of awareness about one's need to improve communication skills surrounding transition with patients, may all contribute to the explanations. Nonetheless, some of these questions, along with further study of the methodology of peer-nomination, may provide a focus for other research studies focused on methodological processes used in qualitative studies.

Interpretation of the data: sharing mortal time

Hearing story: the foundation of presencing and respecting personhood

McQuellon and Cowan (2000) have noted that strength does not lie in stoic, unemotional encounters, but rather in full exposure to one's own emotional responses, including angst. In the Wounded Storyteller–Body, Illness and Ethics, Arthur Frank (1995) states that "one of our most difficult duties as human beings is to listen to the voices of those who suffer (p.25). These are both apt descriptions confirmed by the responses of nurse participants in this study. Presencing for nurses in transitional cancer care demands willingness, vulnerability and skill that starts with listening and truly hearing—hearing that may evoke the human response of deep empathy, of sharing in some aspects of another individual's suffering. It was evident in the responses of the study participants that there was respect for the belief that patients have the best insights about their own story and nurses needed to discover more about that context while interacting in care.

Connectedness as an essential component to understanding the context of a person's story and as an antecedent to discerning readiness for talk of mortal time was a strong thread throughout the interviews. The action of connecting confirms the work of other researchers who have looked at facilitative communication in cancer and palliative care nursing (e.g., Bottorff & Morse, 1994; Bottorff, Steele, Davies, Porterfield, Garossino, & Shaw, 2000; Davies and Oberle, 1990; Parle, Maguire & Heaven, 1997), and is integral to facilitating transition. Connecting acts as an invitation to nurses to recognize and respect the whole person who is living with advancing illness. The exchange is like a drawbridge that allows the nurse into the narrative of the patient so that while other nursing activities that are required (e.g., treatments, teaching, assessing symptoms and functional ability to participate in the activities of daily living, or perhaps reviewing lab results together) take place, there is a context of respect, trust and understanding.

Participant nurses indicated that patients need to know they matter, and this finding is congruent with the following study summation. Having questions taken seriously and being given time to express them while feeling assured that health care providers (nurses and physicians) are there to help and give attention to the person as patient, were all elements of care deemed important by a group of individuals living with cancer (Uitterhoeve, Duijnhouwer, Ambaum, & van Achterberg, 2003). Though patient participants in their study had expressed satisfaction with care generally, they also pointed out that communication was too often focused on technical aspects of care. This stood in stark contrast to an observation that had occurred to me while analyzing the data of this study.

That is, while the nurse participants had referred to certain diagnostic, prognostic and physical signs of functional decline as indicators for readiness, the interviews were much more centered around their concerns and observations about psychosocial and spiritual aspects of care that needed assessment. This led me to wonder if this focus reflected a difference between a general sample of cancer care nurses of varied levels of competence, or if it was reflective of more advanced competence and expertise. Bakker and Fitch's (1998) survey of Canadian Association of Nurses in Oncology membership would confirm communication with patients as a general priority of stated interest. The question remains, reinforcing the need to attempt theoretical sampling in another study.

Early in the second half of the past century, seminal works such as those of Glaser and Strauss (1965, 1968), Kübler-Ross (1969), and Sontag (1979) reflected growing awareness of the need to study the nature of the interaction of those who are care providers with those who are chronically ill and dying. Awareness stimulated further works (e.g., Buckman, 1988; Degner & Beaton, 1987; Faulkner and Maguire, 1993; Wilkinson, 1991) which centered on communication skills and other competencies that health professionals need to acquire in order to be effective, particularly in sharing "bad news" or in discussing the implications of advancing illness and treatment decision making.

Few publications use the term *discernment*; but the need for such insight is conveyed by authors such as Robertson (2000) in her book, Meeting death: in hospital, hospice and in the home. She states: "Attentive listening requires sensitivity to nuance, emotion, facial expression, and body language. *Listen. Shut up and listen*" (italics are Robertson's, p.111). Her injunction emphasizes the findings in Theme A1, and is nicely linked—and succinctly said—with the factors described by participants as essential to the discernment process.

Interpreting story: Discerning readiness and broaching issues of mortal time

Discernment is a matter of truly *noticing*, not just seeing, and of *hearing*, not merely listening; for not *all* nurses notice or grasp the totality—along with subtleties and nuances—of all situations in the manner that *expert* nurses are able to grasp the implications of things. This study's theme of discernment supports this thinking about expert practice in a number of additional ways.

As health care providers in cancer care there is a felt need to know with better certainty when the timing is "right" for introducing issues of mortal time, thus avoiding consequences that Glaser and Strauss described as "a disquieting feeling of having missed certain steps" (p. 26). Findings of this study add to the body of related knowledge about timing. The literature review clearly demonstrated the common belief that timing is complex, an observation confirmed in the tensions about timing that were described in Chapter Four. The bottom line seems to be that there *is no* panacea about timing. Up-front approaches may work well for some people, in some circumstances, but there is still a need to respect personhood, and to acknowledge the complexity of some of the contextual factors which were explicated in Chapter Four.

Determining where ILWPC were in their information seeking behaviour and how they preferred to be told news about their illness, contributed to mutuality in grasping the situation for both nurses and patients. If certain readiness behaviours were evident, nurses would use those as an invitation to continue further, easing gently into matters of concern related to the advancement of illness and increasing awareness of mortal time. The use of "how" and "what" questions were reflected in the findings, marks of communication that a study by Yates and associates (1998) connote as encouragement to keep discussion going (Yates, Hart, Clinton, McGrath & Garty, 1998, p.406). The nurse participants in this current study reflected respect for the ways in which individuals may filter out certain untenable information until they are ready to be responsive to its implications. The hoped-for consequence is facilitation of as healthy an experience of mortal time as possible, one marked by reasoned respect for the personal goals and quality of life indicators of ILWPC.

Issues of protection of hopefulness were paramount in the findings, an issue consistent with the literature review of Chapter Two. But dashed hope was not always a response of the patient that nurses had control over; and that helplessness in the participants was at times a source of concern. Feeling responsible for some level of the emotional responses of patients was a finding that was both surprising yet understandable if the responsibility was perceived to be related to conditions for which the nurse may have some level of influence. That is, having to be the bearer or interpreter of "bad news" when information sharing did not happen under optimal conditions was a source of distress. Too little time, crowded space, confusing language that needed better explanation, difficult family dynamics, or less-than-supportive working teams that left nurses feeling isolated or powerless, were all factors which nurses discussed as barriers to facilitating effective transitional cancer care communication. Similar findings have been noted in the literature (e.g., Chambliss, 1996; Fallowfield, Saul & Gilligan, 2001; Parle, Maguire, Heaven, 1997; Wilkinson, 1991).

Respect for process, for gaining wisdom and understanding of the matrix of concern that feeds collective angst in mortal time emerged frequently as attributes of the nursing role. Relationships which are established and nurtured over time in the outpatient setting served to facilitate the ease of transition in many circumstances because the "knowing" of persons was facilitated. But the length and strength of relationship in knowing another also carries with it a greater sense of not just witnessing as observer but actively sharing the experience of mortal time in a deeper way. That shared experience has implications for the accumulative experiences of grief, too, which are felt by nurses in this setting. At times the relationship with ILWPC paradoxically contributed to the level of angst felt by the nurse, causing greater tentativeness or hesitation in broaching issues of mortal time and on occasion, necessitating requests for another member of the team to carry out that part of the work.

At times, entry into conversation was also led by the clinical nurse specialist whose relationship was sometimes new to the ILWPC, but nonetheless significant and meaningful to both her and the patient and family. Expressions of nurse participants from other studies confirm the benefits that may come from such encounters (e.g. Davies &

Oberle, 1990; Ronaldson & Devery, 2001). Thus, while *duration* of the nurse-patient relationship *over time,* and "*knowing*" the patient was generally perceived to be a significant antecedent to satisfactory consequences—a belief supported by other research (e.g. Luker, Austin, Caress, & Hallett, 2000; Lynn & McMillen, 1999)—narratives from this study belie the belief that *continuity* has been the most critical influencing factor. *Quality*, *astute assessment* and *timeliness* are other dimensions of the interaction which are also significant to the patient and his or her family.

Contextual factors

Encounter effectiveness was enhanced by a fuller understanding of the context for both persons involved in the communication. Sociological literature related to health and illness often refers to the "lenses" through which illness is constructed (e.g., Brown, 1995; Charmaz, 1999; Lupton, 2000; Raphael, 2000). "Lenses" of age, gender, race, culture, religion, family and relational dynamics—including level of support systems, and various other special needs—were referred to by the informant nurses as they described a variety of influences that they perceive shape the readiness of patients to transition.

Age: Two dimensions about age stood out, including where individuals were in their life cycle and developmental tasks, and how closely the nurse identified with the ILWPC and/or the family member(s). When the ILWPC was close in age to the nurse, there was more difficulty experienced in the work of broaching mortal time issues. Nurses also described notable trends among younger patients to be less ready for transition to palliative care services; whereas individuals more advanced in age generally seemed readier to see palliation and end-of-life as a natural turn of events. Younger persons, especially if they were parenting, seemed either more likely to be treatment-seeking in order to leave a legacy that they had "tried everything" for the sake of their families, or less likely to even "go there" in their conversation. While noting these trends the nurse participants couched their observations in qualifying statements and stories which reflected exceptions to these generalizations.

Gender: Expectations surrounding mortal time communication and gender were also evident. The observations of some nurses that it was more difficult to encourage male patients than female patients to communicate more openly about their progressing illness, uncovers potential assumptions—perhaps a social construction of gender response to illness—that may influence responses of some nurses to the communication patterns of ILWPC. Silverberg (1985) discusses the manner in which socialization processes shape expectations, attitudes and behaviours of men, and how North American males may be affected in dying and relating to care providers. Unfortunately there were no male nurses in this study to provide a male perspective on care experiences with ILWPC.

The findings, however, provoke a question. Is silence of male patients about such matters unacceptable? Why did nurses—all female in this study—find this disinclination to verbalize feelings so challenging? Perhaps the silence itself may be speaking volumes to us as care providers. Silence may arise from profound suffering that cannot be otherwise articulated, or because of need for privacy, personal history, or socialization (family, community, cultural or religious expectations), or some other plausible reason. While much has deservedly been written in the last few decades about the need for *women's* voices to be heard in health care, we have also been socialized to expect certain behaviours and responses in men that either quiet their voices as they experience progressive illness, or judge their chosen quietude.

A preliminary scan of the literature in response to the findings affirms that gender issues in cancer care generally, but particularly in relation to transitional cancer care as these findings reveal, is an area needing further research, educational awareness and consideration in nursing practice (e.g., Elmberger, Bolund, & Lützén, 2002; Jakobsson, Hallberg, & Loven, 1997; Moynihan, 2002; Ringdal, Jordhoy, Ringdahl & Kaasa, 2001; Silverberg, 1985). Congruence with this study *was* affirmed in several areas including confirmation that gender differences exist in the experience of cancer, and that men seek support in different ways. Nurses need to be aware of how expectations of gender behaviour colours the experience of care for both the patient and the nurse, and that potential assumptions need to be placed in check.

<u>Systems or organizational influences:</u> Notation in the literature regarding the matrix of organizational structures and interpersonal and interprofessional relationships which add to the complexity of an environment of care, particularly a tendency that transition may be dominated by the medicalization of the dying process (e.g., Berwick, 1995; Chambliss, 1996; Jeffrey, 1995; Marshall, 1995; Shanely, 1982; SUPPORT, 1995), was further supported by this study's findings (Chapter Four, A2.3.6).

Some enabling supports were noted. Recent improvements in a regional palliative care program and availability of "supportive care" (e.g., Clinical Nurse Specialists, symptom control clinics), during cancer care transition to palliation was affirmed by the participants and reflects concomitant developments nationally (e.g., CHPCA, 2002; CNA Standards for Palliative Care Nursing, 2001) and internationally (e.g., Education for Physicians in End-of-life Care, 2001). Nurse participants from teams that functioned well (i.e., effective communication and support among members, acknowledgement of each others' workload, responsiveness to unique situations which demanded flexibility and adaptation, etc.), and clinical areas where there was greater control over patient scheduling, privacy, comfort, and peer and management support of accumulative grief, were able to describe processes that led to enhanced transitional care experiences for both ILWPC and their health care providers.

Negative influences created challenges, however. Conditions which reflected the antithesis of the above-noted factors accentuated the potential for moral distress and perceptions of poorer transitional care outcomes for ILWPC along with their care providers. Marino (1998) documented similar findings about influences on nurses and the effects of cumulative grief such as inadequate resources, unrealistic expectations, poorly defined roles, poor education, work overload, pressures for perfection and lack of opportunities for emotional debriefing. While further development of regional health palliative care programming has occurred, restrictions on registration for persons still receiving palliative chemotherapy has created tension for those nurses and physicians who are providing second third and fourth line treatments to patients for the understood goal of palliating their disease and symptoms. Referral to the palliative care program is often then delayed, sometimes facilitating the tendency to delay discussion of matters pertaining to planning for end-of-life. The hoped-for goal of early enough intervention to facilitate palliative care understanding and program benefits may be deferred because referral to "supportive care" is often associated with specific symptoms of illness progression needing intervention rather than the existential, spiritual and psychosocial dimensions of care. Payne et al (2002) noted similar dynamics from the Sheffield, England experience.

Elements of care such as dignity-conservation (Chochinov, 2002; Chochinov, Hack, McClement, Kristjanson, & Harlos, 2002; Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2002), and skill in end-of-life communication are less likely then to be facilitated particularly in the context of having to care for many persons in time-limited appointment slots if there is rigidity about "keeping up." Participant nurses functioning in these circumstances seemed set up for less effective communication and comprehensive care based on more superficial interaction because of limited resources or supports in the immediate system.

"Blocking" in communication (e.g., Maguire & Faulkner, 1988; Maguire, Faulkner, Booth, Elliot & Hillier, 1996; Wilkinson, 1991) or use of language that is threatening rather than fortifying (Friedrichson, Strang & Carlsson, 2002) may shut out readiness cues. While the nurse participants in this study demonstrated their insight and communication skills in the interview process, it is also reasonable to infer that systemic or organizational barriers will hamper quality patient care. Less expert nurses may not venture into more complex communication encounters if the environment is not supportive to allowing adequate time, mentoring and education, and a debriefing process. If nurses are unable to consistently meet their personal and professional expectations for spending time with patients in order to discern more discreet matters of patient and family concern, they too will suffer moral distress and or moral residue (Jameton, 1995; Webster & Baylis, 1999). Leaving the field or distancing from ILWPC may be the detrimental outcome.

Discernment and language

Use of terms such as "palliative," "transition," and "supportive" were used differently and had differing applications in this study even among the nurse participants who worked within one organizational culture. This variation in ascribed meaning was consistent with findings of Payne et al. (2002) in their review of services in South London. Buckman (1992) spoke pointedly about ensuring the avoidance of "medspeak" or "nursespeak"—language that "is intelligible only to the initiated" (p.83). Thus for practitioners, "palliative" may connote a philosophy of holistic care or a system of support to which persons can be referred. For the person having that option presented to him, it may mean "I'm going to die soon." Meanings associated with the question put forward by Jeffrey (1995), regarding when appropriate care begins, influence the interpretative stance varied professionals take on the definition of the term and services of "palliative care." Interestingly, some nurses in this study thought that "palliative" was a term that had medical model connotations, while "supportive care" was easier to use from a nursing perspective. This challenged my thinking. My personal bias had been that the term "supportive" could be confusing as *all* cancer care–including that which is offered to persons whose cancer is deemed highly curative—ought to be supportive in its intent. My language bias had also been influenced by thoughts that "supportive" may at times be used as a term to disguise or postpone mortal time talk because of the reluctance to initiate thoughts of palliative care and the anxiety that may evoke in ILWPC.

Certainly, the findings confirm that some persons are not ready to broach mortal time at points in their illness continuum when there may be effort to shift their level of readiness according to professional views of that timing. As the findings demonstrate, however, sensitivity to timing needs to be honoured and respected. Conversely, professionals in cancer care also need to be vigilant about opportunities to prepare

ILWPC for inevitabilities, too. Nurses spoke about how they would work around the language so that it was moderated, aligning with patient goals and understanding, rather than being so open and direct that it became threatening (e.g., the use of "supportive" care versus "palliative" care). These strategies are synchronous with trends of "conditional disclosure" (Field & Copp, 1999) and use of "fortifying" language (Friedrichson, Strang, & Carlsson, 2002).

Preparing for mortal time

Arthur Frank's (1995) observation that patients need to tell their *own* story rather than just to retell it in the manner the medical record or the physician as primary spokesperson may tell it (p.5-6) was underscored by many of the nurse participants' stories. Norton and Bowers (2001) have suggested *shifting* the decision making to a perceived "realistic" treatment direction as decided upon by health care professionals. Mary dealt with their suggestion somewhat differently, in a way that honoured patient autonomy more clearly, even when patients' choices were different from what she might choose herself in similar circumstances. Rather than seeing a young mother's decision to spend more time away from home in order to receive treatment as "unrealistic," a term that participants in Norton and Bower's (2001) study might apply to the situation, Mary supported the patient, respecting her view that she was creating either a "miracle" or "a legacy of trying" for her children. Mary's only injunction was that nurses needed to ascertain that patients have made an *informed* decision based on adequate and full information.

While nurse participants tended to be supportive regardless of the patients' decisions, they admitted it helped to understand the factors influencing the rationale behind the decision. Gathering the facts contributed to nurses' trust in the decision making of the patient; conversely, the patient felt that efforts to know him/her were being made, a quality about care that has been supported in other studies as being important to patients (Luker, Austen, Caress & Hallett, 2000; Tanner, Benner, Chelsea, & Gordon, 1993). Furthermore nurses' knowledge of the clinical facts and an ability to provide helpful informational support was pivotal to patient trust. For example, listening to the contextual history of a "really ugly death" in this study provided the appropriate focus on dispelling fear through teaching about analgesia, the interpretation of diagnostic results, and information about access to improved palliative care supports over what had been experienced in the past. The nurse's acknowledgement of the patient's and family's personal story, however, had been key to the mutual trust which developed out of this scenario. It is in "small moments" such as these that ethical and moral practice are manifested (Frank, 1992). It is also in small moments that "doors begin to open," or that "seeds" for future discussion are "planted." Such opportunities in which there is openness and a willingness to "follow the patient's lead" create a context of caring and trust for future processing of transitional tasks.

Not all scenarios have positive endings, however. Tensions about initiating these conversations or having to deal with angry responses, dashed hopefulness, and care suggestions that are declined leave nurses with feelings that may create guilt that they ventured in through what they *thought* was an "open door" only to have it closed in anger, fear, withdrawal or uncertainty. These after all are the emotions of the roller-coaster Tefs (2002) and others have described (e.g., Gregory & Russell, 1999; Mayer, 1998) about transitional cancer care.

Despite formalized teaching and normalizing of certain possibilities and providing information, however, it was evident in the findings that ILWPC did not always accept information offered. Declined options were at times a source of distress in the nurses and others on the care team as they struggled with consequences of what they felt may have been unnecessary suffering. Similar observations were noted by Dunlop and Hockley (1998, p.97). On the other hand, transitional cancer care nurses are witnessing and empathizing with suffering that they may *not* have ability to relieve. Numerous authors have written eloquently about the paradoxes of suffering (e.g., Charmaz, 1999; Frank, 1992, 1995; Gregory & Russell, 1999; Kleinman, 1992, Sontag, 1979, 1990; Younger, 1995), including observation that the suffering person is often alienated from others, even from self. Narratives cited throughout Chapter Four are reflective of this witnessed suffering.

Sharing mortal time: processing and facilitating awareness

Having a desire to come alongside individuals whose suffering *may* be alleviated, at least in part, was identified as a motivating reason to support people who were "turning the corner" in their readiness to enter mortal time.

Yurk et al. (2002) noted the variance in stability of decision making in ILWPC as new information or new caregivers change the reference points and changing needs emerge. Their study with focus groups of seriously ill persons and their family caregivers underscores the need for discernment and skill in responding to the changing needs of ILWPC, needs identified by the nurse participants in this study. In addition to the descriptive phrases of that phenomenon within transition (e.g., "changing pace," "switching gears," "turning the corner," "going down a new road"), the nurses noted the importance of allaying the fear of abandonment, while coming alongside with ongoing informational, emotional, relational, and spiritual support. This support included:

- clarifying the individual's awareness, understanding and meaning of his or her advancing illness
- letting ILWPC direct what they wish to know and how they want their care providers to approach things like decision making and /or timing of certain interventions (e.g., when they would feel the need for home care, or a hospice volunteer)
- referring to others in the team and /or other community resources, liaising, negotiating systems, and contributing to care planning, intervention, evaluation and modification as needed
- mapping out the possible journey ahead, being truthful without being "brutally honest"
- anticipating needs and being proactive in assessment and planning
- encouraging reflection about "taking care of business" if readiness is discerned
- ensuring timely and effective symptom management
- repeating information over time as shifting the bigger picture and reframing of hope evolved
- being there in sensitivity and respect for the integrity of personhood.

Their descriptors confirmed the view of McQuellon and Cowan (2000) that turning toward death together in authenticity can enhance meaning for those who share the experience. There was congruence among the nurses that support should not be prescriptive; rather there needed to be an invitation to self-direction in care for those who were competent to do so.

Doing the right thing right

The observation that narratives elicited much information about the manner in which the nurses understood their role in transitional care, is closely aligned with a number of studies in communication of death and dying. Lefty and Maynard (1998) focused on the profoundly *social* nature of "interactional caution" in physician discussions about death and dying without explicit use of those words. The importance of research emphasis on *how* news is conveyed (Ptacek & Eberhardt, 1996) was underscored by the nurses in this study. While the literature is limited in its' exploration of what happens in the *nurses'* experience of mortal time with ILWPC when patients choose *not* to access palliative care services, this study revealed rich narratives about nurses' responses to such circumstances.

The transcripts from this study were replete with implicit integration of professional nursing values (Code of Ethics for Nurses, 2002), and explicit identification of the notion that nurses desire to do the right thing. In fact that moral imperative was central in their reflections and narratives. Benner (1991) notes that paradigmatic cases provide texts for interpretive study of "ethical comportment, practical moral reasoning, and ethical distinctions" (p.3), indicating that the richness of narratives is often associated with higher levels of expertise of the storyteller. In other words, qualitative distinctions and ethical concerns embedded in storying are associated with higher levels of reflexivity and expert practice. Her comment that "in complex human relationships there is no way to get it right without sometimes getting it wrong" (p.10), resonates with these findings, affirming that learning from risking actual dialogue in actual situations must be a part of ethical discernment. Benner (1991) also reminds readers that:

> Norms and principles may give clues about the importance of timing, but historical knowledge of concrete situations is required to learn the issues of timing... Attending to patient and family readiness cannot be free of the risk of imprudence, paternalism, or misunderstanding. Skillful focused attention, listening, and ethical comportment that seek to be faithful to patient and family concerns are the only correctives available to the practitioner (p.10, 11).

This description of the "narratives of learning the skill of involvement" are reflective of what was ascertained in the narratives and exemplars of this study's participants.

Facilitation of patient autonomy, for example, was a matter of importance to the expert nurses of this study. In keeping with Benner's thoughts above, and in context of the core question about the complexity of timing discernment in this study, the findings illuminate that need to take greater professional risk (e.g., Theme B1, Chapter Four, FG2J707) in trusting the judgments and timing of ILWPC and their families, in recognizing our limited knowledge of their social, historical and relational construction of their "knowing," and in letting go of our parentalistic need to control the outcomes of our encounters with them as whole persons in mortal time. *Sharing* the experience with them does *not* mean that we can or should *control* it. Beauchamp and Childress (1989) point out that respect for autonomy is not merely attitudinal; it involves enablement of persons to act autonomously based on their personal values and beliefs (p.71).

Nurses in this study demonstrated support for Parker's observation about relational ethics, in that they had learned from patients that their story lines do not always "fit neatly into the conventional version of what it is to be ethical" (Parker, 1990, p.34).

Mary had found herself conflicted, for example, with the situation in which a patient in confidence shared that she was proceeding with BMT (despite doomed odds for survival of the intervention and the knowledge of potential suffering from undergoing the bone marrow transplant) solely for the sake of her husband. The patient, it seemed, had entrusted the nurse with this information because she needed to talk with someone, not because she wanted anything done to change her decision. Autonomy, truthtelling, beneficence-nonmaleficence, distributive justice, and the valuing of both the dignity of this woman and her husband were all ethical dimensions of the dilemma for Mary as she reflected on the patient's decision.

Zerwekh (1992) refers to protection of the vulnerable (i.e., persons who have a "compromised capacity for autonomy," p.104) as "a way that maximizes and develops self-determination," noting that such skill "is exquisitely complex" (p.104). Absence of such skill may lead to the dangers of "inexcusable coercion and paternalism" (p.105). Mary's dilemma in the preceding paragraph, along with stories of other expert nurses in this study often poignantly revealed a "holistic conception of ethical deliberation" (Parker, 1990, p.37), laudable discernment in the face of exquisite moral and ethical complexity—a context of perplexity that could not afford rational detachment.

Other dimensions of ethical behaviour were evident. Concerns were raised about balancing the needs of individuals in context of systems that must also consider universality and justice (Beauchamp & Childress, 1989, p.243-46). Resources are limited and must be fairly distributed. Disparities in time and space constraints, peer support, and workload control created tensions and moral distress for some of the participants. Others recognized the issues and felt a sense of commitment to advocate for change.

Truthtelling, especially in the context of cultural differences and expectations, but not exclusively so, was another challenge ethically. Buckman (1992) advised that it is much more distressing to deal with illness if unprepared for it than to deal with the distress of the truth (p.195). But a nurse expert in this study took Buckman's recommendation further. While acknowledging instructions from a patient's family about their cultural beliefs about illness and truthtelling, the nurse validated what *his* wishes about receiving information actually were, ensuring that health care provider actions were in keeping with what *he* actually desired. In this manner she was able to advocate for his *right* to know, while respecting his autonomous *wish not* to know. In the process his family members as well as himself were treated with dignity in a manner that respected his personhood.

The nurses' stories in this study emphasized the complexities surrounding moral and ethical behaviour, and the need to check assumptions about the "shoulds" and "oughts" of experiences in mortal time. Enabling others to "do it his/her own way" can be ethically and morally distressing situations for nurses as they struggle to tease out, and uphold competing ethical values (CNA Code of Ethics, 2002) and a relational ethic of care (Parker,1990).

Creating or shaping solutions

Nurses are urged to "advocate for practice environments that have the organizational structures and resources necessary to ensure safety, support, and respect for all persons in the work setting" (CNA Code Of Ethics, 2002). This, too, is a challenge for nurses, if an environment of peer support is compromised and hierarchical structures restrict what the nurse may perceive is "best practice." Caring for others is more difficult if the work you do is not valued or understood. Potential for workplace conflict and personal sacrifice leads to demoralization in the work environment, and thus less inclination for giving of energy to patients and families. Some of these tensions were noted in this study. The nurse participants offered a number of suggestions for reducing tension and moral distress, including:

- learning from case studies or shared exemplars
- team assessment and decision making to enhance timing, informed consent, and comprehensive knowledge of the person with whom care is being planned
- debriefing sessions, especially in extremely difficult situations
- educational sessions about the variety of lenses through which the illness is socially constructed (e.g., culture, religion)
- team collaboration and support in the face of limited personnel, time and space resources
- advocacy for ILWPC who declined the offerings of "best practice," adapting and learning to take risks within the context of peer professional expectations
- acknowledgement of grief and formal recognition of the need to support each other in the experience of cumulative loss.

Chambliss (1996) has written powerfully about the role of nursing in ethical health care being hampered, even silenced by nurses' lack of power in the decision making that influences what they must actually carry out. He writes that serious discussion of nursing ethics needs to deal with the realities of organizational structures—observing that nurses at times are needing to "cajole, trick or badger a recalcitrant system into doing what ought to be done" (p.7). The system itself may actually be the creator of many of the nurse's ethical difficulties. Thus attempts at individualistic solutions to ethical issues, creating a "detachment of self from its own behaviour" (p.11) are ineffective. Ethical analysis of organizational behaviour is necessary to create lasting and appropriate solutions.

Benner's (1991) discussion of the role of experience, narrative and community in skilled ethical deportment supports the use of this study's expert nurse exemplars as a way of illustrating learning and providing sustained understanding of practice and ethical issues. Her call is to public storytelling (p.19), so that the ILWPC is seen as a member and participant of a community, not just a singular person with needs in isolation or in competition with those of others. Shaping ethical solutions may be enhanced by closing the gap between theoretical and practical moral reasoning, a gap that Benner describes as "containing all the lived examples and narratives of what the ethical distinctions look, sound, and feel like when they are expressed in actual situations" (p.18).

Differentiating roles: the nurse-physician dyad

Development of role expectations between nurses and physicians has been influenced by the social construction of gender roles, power structures and the historically pervasive supremacy of the biomedical model. Though challenges to underlying suppositions continues to effect change it was evident from the findings in this study that comprehensive alteration of these constructions has not yet been integrated into all areas of cancer care practice. In fact, because of the very complexity of the nature of transition (a phenomenon that requires clarity, collaboration of team, time, and sensitive awareness of personal story), the difficulties arising between nurses and physicians can either be exacerbated or demand analytical attention. That is, when the dyad is healthy—working smoothly and to the benefit of all concerned—we need to figure out *why* it is functioning so well so that lessons are learned.

The voices of these nurse participants are significant because their collective narratives indicate that many have taken leadership roles in care of ILWPC, some prompting attending physicians to consider palliative care when that option was not explicitly being offered. The nurses' narratives challenge an omission noted in articles on physician communication (e.g., Baile & Beale, 2001; Buckman, 1992) who suggest that their peer physicians recommend referral to social workers or counselors as a source of support for patients living with cancer. The role of the nurse in care was invisible in this context—a phenomenon at times observed in listening to nurses themselves.

Such omissions have left me wondering *why* that had occurred. Is the role of the nurse that easily missed? Was the nurse in oncologic care perceived only in a role dominated by "tasks" such as the provision of chemotherapy? Yet, as borne out by the findings, it is often the nurse who may know the patient better than any other care provider on the health care team. Their nuanced awareness of the patient's personal story and the many contextual factors that can influence decision making in the person's transition to palliation often led nurses to initiate change in the focus of treatment goal-setting. Indeed in several stories, it was the nurse who was asked by the family to be the person to share the information about palliative care with the patient. This finding reinforced the suggestion of Buckman (1992) that the person who shares bad news with a patient should ideally be someone who has expertise and a continuing responsibility and commitment to the patient and /or relative.

Much of the nurses' provision of insight centered around the questions of how, by whom, and when facilitation of transition and referral to palliative care does—and optimally should—happen. All the participants expressed views that underscored the assumption that nurses *are*—and *ought* to be—involved in assisting ILWPC with transition to palliative care services. One nurse had expressed surprise that there were still nurses in her work environment, nurses who were not a part of this study, who expressed that the sharing of information about palliation and end-of-life issues such as resuscitation and advance health directives was the purview of physicians alone. The nurse participant had rationalized this view as representing a level of professional and personal discomfort or inadequacy in sharing such communication. Reluctance is not an isolated influencing factor on the broaching of end-of-life matters (e.g., McGrath, Yates, Clinton & Hart, 1999). Some authors have pointed out the expressed need for nurses (and physicians also) to improve their skills so that "blocking" of open communication in the cancer care setting, evidenced by behaviours such as denial, avoidance, unrealistic optimism, interference, and a focus on physical rather than psychosocial and spiritual care needs, is lessened (Booth, Maguire, Butterworth & Hillier, 1996; Booth, Maguire & Hillier, 1999; Bowman, 2000; Craven, 2000; Buckman, 1988, 1992; Heaven & Maguire, 1996; Maguire, Booth, Elliot & Jones, 1996; Maguire, Faulkner, Booth, Elliot & Hillier, 1996; Maguire, 1999; Maguire & Faulkner, 1988, 1993; McGrath, Yates, Clinton & Hart, 1999; Ptacek & Eberhardt, 1996; Thorne, 1988). (Strategies for such learning from the relevance of this study, are offered in the recommendations section of this chapter.)

It is also clear from the literature that the broader public view is not aware of the capacity for nursing involvement in end-of-life decision making (e.g., Aranda, 2001; Satir et al., 2000; Storch & Dossetor, 1998; SUPPORT Principal Investigators, 1995). The physician is still perceived to be responsible for initiating discussion in the majority of circumstances. Owens (2002) suggests that patients still depend on the oncologist and cancer care team to initiate the discussions (p.184, quoting Larson & Tobin, 2000; Balaban, 2000; Detmar et al., 2000).

It was clear that the nurses in *this* study not only participated in such discussion, they led them. But broaching matters important to end-of-life was not treated lightly as they described how they prepared themselves for the interaction and then debriefed with their peers—in areas where that was encouraged through peer support—following difficult emotional challenges in the encounters with patients and/or families. They felt strongly that it was an important part of their role, especially because they were in a place of ongoing relationship with most of the patients. Similar views were expressed by the participants in the study by McGrath, Yates, Clinton and Hart (1999).

What has been most surprising to me is the recognition that nurses themselves do not always identify the significance of their role in facilitating transition (e.g., K63, B1.3, Chapter Four). This finding was similar to an experience that I had at the Mayo Clinic. A treatment nurse there described all the supports that were available to outpatients but never once mentioned her own role or that of other nurses. Yet their role *was* significant. Katie, for example, was also a "treament nurse," and as the researcher analyzing her transcript, I can attest to her tremendous insight and expertise. Her comments and stories were laden with evidence of reflexivity, a mark of clinical maturity, and ways in which she supported patients and their families.

Reflections on mortal time: nurses stories of personal vulnerability and maturation

From the interviews with the nurses, it was evident that living vicariously in mortal time had poignant, *long-lasting* effects on them both personally and professionally. Matters of life and death call out for serious contemplation about intentions and consequences of care, and that sort of thinking in the participants was unmistakable. Memories of stories remained sharp in detail and subtlety. Benner (1991) reflects similar characteristics in the nuanced narratives of nurse experts, comparing them with the accounts of non-expert experienced nurses whose narratives lack the richness and "qualitative distinctions and ethical concerns" (p.3).

As we recall the events of a day and when we try to understand what has happened to persons for whom we care, we are reflective. But when we try to understand what has happened to ourselves and how we may have affected that encounter, we are reflexive (Reynolds, 2003). Recalling Jenna's story of the man who died alone and whose family would not come to attend him in his dying, I wondered if her expression of sadness was an expression of grief that many people both live and die in a state of isolation, and of hurting relationships that may never be healed. So while we work to contribute to healing of the body from cancer and are unable to do so, we also carry sadness that we also cannot always facilitate healing of personhood. As nurses we are left with "doing the best we can," and coming to grips with the awareness that suffering does not lend itself to fixing (Frank, 1992).

Rich, detailed descriptions of how and when the informant-respondent nurses approached the work of mortal time have been illustrated in depth in Chapter Four and explicit examples of reflexivity noted in B2.1. As I listened to their narratives and descriptions of their work I was deeply affected. They were their own stories of professional life, blended with the recitation of stories of their shared experiences with individuals for whom they cared, persons and families who lived with the knowledge of progressing and incurable illness. The poignancy and detail with which the participants were able to bring to mind memories and perceptions of situations related to the discussion at hand in the interview process left me challenged as the researcher to know how much to remain "neutral" in the interest of protecting the data from researcher bias or influence. Some of that challenge was likely related to the limitation of my own inexperience as a researcher. I was living with the fact that as a nurse manager—still with much patient contact and involvement in the lives of people living with advanced disease—I found my thoughts and emotions resonating with so much of what was said. Reflexive exercise after each interview was needed to remain vigilant about avoiding imposed bias while still remaining attentive to the nuances of the non-verbal data that infused the interview process.

At times, I was also distressed. For example, when one participant indicated a sense of feeling responsible for things "not going well" because of the outcome of tears of a patient who had just been invited to talk about a palliative care referral, I wanted to interrupt the story and intervene to reassure her that the tears of the ILWPC were both normal and acceptable in the face of processing mortal time and that perhaps she did not need to carry a burden of guilt regarding her role in this situation. There were times when I shared tears of empathy or light-hearted laughter because I was not only human but also felt professional kinship with what was being expressed. Such situations of inner tension about my role as the researcher underscored the very complexity that the review of the literature, as outlined in Chapter Two, had confirmed in trying to untangle the matrix of care in the midst of transition into mortal time. McQuellon and Cowan (2000) had articulated it well—this work is *not* for the "faint of heart."

Reactions of patients such as anger, blame, tearfulness, were so deeply felt that at times the nurse participants acknowledged they were tempted to assume responsibility for these difficult reactions more than just as witness and empathizer. It was in those moments that there was recognition of the need for vigilant support and debriefing as a team for those who bear "bad news" on a regular basis. If this is not done the accumulation of moral distress may create an environment where care givers leave or begin to block their own emotional responses to individuals who are in need of their emotional connectedness (e.g., Marino, 1998).

Recommendations

Issues related to rigor and the study limitations were thoroughly discussed in Chapter Three. A caveat to generalization of the distribution or frequency of these findings to possible responses of other nurses in cancer care must be acknowledged given the small size of the sample and the purposive selection by peers of nurses considered to be among the expert group of practitioners in the provincial cancer care organization. However, given general saturation in the data, thick with description and "rich" in depth and insight about the complexities of transitional cancer care, the findings are worthy of consideration of a number of recommendations in the areas of nursing education and practice, administration of health care systems for persons living with progressing cancer, and nursing research.

Nursing education and clinical practice

This study has contributed to nursing knowledge of the nursing role in transitional cancer care, describing the complexities and challenges encountered while caring for ILWPC. Educating nurses to improve discernment of readiness behaviours will lead to better responsiveness to needs of ILWPC. Thus, a number of recommendations for nursing education arise from the findings.

Teaching about the foundational importance of nursing presencing, active listening, use of therapeutic self, and respecting the total personhood of individuals and families for whom we care is essential. It sounds so basic. But the goal is not always able to be actualized in work environments that are governed by others (Chambliss, 1996) and that are replete with suffering and the experience of transition with its attendant chaos, loss, shock, uncertainty, fear, anger, despair, generalized angst, sadness, and withdrawal. Nurses must be prepared through their initial, and then continuing, educational experiences to understand concepts such as transition and the impact of receiving devastating news. Professional values (e.g., CNA Code of Ethics, 2002) and how to advocate for their integration into practice must be discussed and explored. Learning about concepts such as readiness discernment, or dignity conservation (Chochinov, 2002), or cumulative grief (Marino, 1998) provides insight into a matrix of learning needs that must be addressed in the curriculum of nursing in transitional cancer care in addition to the more readily defined interventions related to symptom management associated with disease progression. Learning to value each other as nursing peers who are working to use themselves as persons who contribute to the respectful holistic care of others is integral to that educational process. Thus education must also include a focus on supportive team functioning and respectful interpersonal communication essential to quality care.

Another recommendation offered by the nurse participants is that adequate time be allocated for the mentorship of nurses newer to the field. By partnering them with nurses who have advanced skills and sensitivity in the area of discernment and communication about end-of-life matters, invaluable learning can take place. Reflection and shared discussion about the interaction after an encounter arising out of disease progression and treatment decision making, for example, may provide helpful insight and learning for the nurses involved. Fallowfield, Saul & Gilligan (2001) have described a two-day course curriculum that addresses some areas of communication skills important to nurses in cancer care.

Nurse participants in this study identified concern about harming the person if broaching the topic was perceived in a manner that “dashed hopefulness” as a barrier to initiating discussions about palliative care. Parle, Maguire and Heaven (1997) reinforce the idea that improving nurses’ communication skills when dealing with persons with cancer—especially when dealing with complex issues such as breaking bad news or introducing the idea of palliative care—may diminish the use of avoidance or distancing behaviours. This study was based on the experiences of nurses felt by their peers to be expert in communication; yet even they as a group admitted to areas of concern and wanting to evaluate their own effectiveness in doing the right thing right. The findings then confirm the need to introduce both formal and informal educational strategies (e.g., seminars, role playing, shared stories, debriefing and reflection, sharing encounters with patients with another peer and then seeking feedback) to enhance competence and thus confidence in sharing mortal time issues with ILWPC.

Wilkinson (1991) found that there was correlation between blocking behaviours and nurses who had the least self-awareness or knowledge about these behaviours. As part of the design of this study, nurses of all levels of expertise were invited to volunteer for a focus group which was going to explore communication in transitional cancer care; only three nurses volunteered—nurses who had already been nominated as "expert." Whether or not this interesting outcome is support for Wilkinson's findings cannot be determined at this point, but it raises the question about needing to explore strategies to assist nurses in assessing their own personal awareness or knowledge of effective communication skills and whether or not they are incorporating them into their practice.

Communication skills that promote the telling of the patient's full story—not just their health history—so that their contextual life values and relationships, and thus personhood, can be better known has been demonstrated by the findings to assist nurses in honouring autonomous and/or shared decision-making processes according to patient wishes. Educating nurses to continuously challenge their thinking and assumptions about the social construction and ascribed meanings of gender, family, culture, religion, socio-economic status and language as factors which influence persons and their expectations and decisions in care relationships is critical to professional maturation. Nurses function under the strong influence of the medicalization of health care. The lived experience of advancing and chronic illness is not just a medical matter, however; nor is living in mortal time. It is recommended that nursing education expose nurses to thinking about the social and spiritual contexts of illness and caring. This study demonstrates how we need to be vigilant about challenging the systems of care in which we work to be more responsive to whole personhood and community need.

Awareness of the power of language and meanings that can be aligning or alienating is also an area where nurses can advocate for persons receiving care within systems that frequently assume certain understandings about the words or terms used in everyday work. The findings of this study indicated differences among nurses from the same organization in their ascribed meanings for terms such as "palliative care." Examination of the language we use and reflecting on how that language affects others is another area needing further education and exploration in practice.

Thus, continuing education is recommended to enhance competency in all areas of transitional cancer care provision, particularly in discerning readiness behaviours, significant contextual influencing factors, and in mortal time communication. Furthermore, assessment of how well that learning is being integrated into practice provides a level of accountability to self and to others who are recipients and partners in our communication encounters.

Education related to the incorporation of nursing ethics in practice is another area of recommendation based on the findings. Two themes offered from the findings had to do with foundational integrity in nursing practice. Nurse participants expressed sensitivity to their moral agency in wanting to do the right thing, and to do it the right way. The awareness of ethical principles, of the values which are embedded in the national professional Code of Ethics (CNA, 2002), of exemplary practice, and of the application of the "golden rule" (i.e., that one should act in a manner in which oneself would want to be treated given similar circumstances), was pervasive in the findings.

Respect for the choices of ILWPC, as whole persons with unique stories, for their autonomy in decision making, for the upholding of truthtelling in the process, for advocating for patients even when that meant standing up to persons (i.e., other professional care providers, especially those with greater power and authority in the system of care) were all ethical actions that nurses aspired to practice. Dilemmas in care—usually based on respect for two or more competing values—however, were also identified. Education supporting the working through of these dilemmas is essential to assisting nurses to understand their moral agency in cancer care. Without such education and support, unresolved moral distress will lead to moral residue. Thus, nurses who are unhealthy in their work environment and personal growth will eventually provide less optimal care for patients and their families, a phenomenon that contributes to a demoralized and compromised environment for care.

Nursing curricula should emphasize the importance of understanding that patients and their families know themselves "best," and that our professional wisdom and experience is brought into the health encounter as a gift to be offered. The findings stand as a reminder to nurses that we may need to relinquish certain assumptions that we make of each other and of patients about what is "best practice." We must be vigilant about letting go of traditional views that lead us into control issues based on perceptions about who bears—or "should" bear—responsibility for the burdens of difficult decision making. The findings help nurses to recognize that *every* encounter we have with ILWPC, their social family members and our team of health care provider peers is imbued with the necessity of moral agency.

Reflection and reflexivity are exercises that need to be taught and better drawn into the processes of everyday practice in transitional cancer care. As the exemplars and summative comments of the nurse participants reflected, the use of narrative as a teaching approach and as a therapeutic intervention is invaluable in processing the inevitable grief which comes with the work of transitional cancer care and palliative care. Learning to seek balance in life and to value the importance of healthy self-care is learning that may take time for nurses to fully comprehend and assimilate into daily living. They are lessons that are deeply influenced by nurses' personal frames of reference. Exercises promoting reflexivity and self-awareness may need to be validated by peers and superiors in order for assimilation of self-care practices to develop.

Educational strategies identified here are not meant to be limited to formal undergraduate and continuing educational processes for nurses. Rather there needs to a commitment by organizations to promote a culture of ongoing supportive learning environments that are creative, adaptive and willing to explore numerous approaches to enhance competency, reflexivity, moral and ethical practice, and formalized acknowledgement and support for the emotional stressors inherent to working within a framework of mortal time experiences.

Administration of the systems of care for persons living with progressing cancer

Nurse managers, administrators and organizations must advocate for the optimal care of persons living with cancer, challenging others in positions of joint or broader system and organizational responsibilities to designate resources for educational and care provider health supports into operating and capital budgets. If we are truly committed to patient and family centered care, then hearing the patients and integrating their contextual stories into shared care decision making must be facilitated. Adequate time and space are environmental factors that nurses identified as either barriers or enhancers to communication and care for ILWPC and their families.

Nursing input into systems of care must be heard. Their insightful observations and poignant narratives are teaching tools that raise awareness of the joint needs of care providers as well as the persons being cared for. Deleterious power relationships that hinder collaboration in care provision must also be attended to and the voices of nurses heard. They are strong advocates for persons living with cancer and facing end-of-life. Nurses with developed expertise in transitional and palliative care should be acknowledged, affirmed and supported in positions as mentors for other nurses whose potential for enhanced competency may be slower to develop if attention is not paid to their ongoing educational needs. The discernment skills of expert nurses should also be tapped through formalized processes of debriefing, reflective analysis, and participation in ethics rounds and committee membership and organizational decision making.

Patterns of nurses leaving the field need to be carefully evaluated. Both the literature and findings of this project validate the correlation of moral distress and accumulative grief with conditions of nursing work that had become unhealthy. Indeed several participants were in the process of contemplating a different expression of their nursing at the time of this study, despite the fact that they were considered by their peers to be exemplary cancer care nurses. Others in the study had acknowledged tearfulness in the course of their day as a regular—sometimes daily—experience. That was a finding of concern to me as both researcher and nurse manager, a concern worth exploring and evaluating more closely. It is recommended that ascertaining whether the regular expression of tears was merely evidence of :

- legitimate empathy at a healthy level
- poorly defined boundary setting in the context of long term care relationships
- workplace issues in which nurses are feeling powerless
- overload and impending burnout
- unattended, unacknowledged accumulative grief and /or moral residue that has reached an intolerable level, surpassing the inner resources or hardiness of individual nurses.

Systems of health care provision in which workers are faced regularly with the suffering of others must find ways to acknowledge ongoing grief work and find other ways to support the inherent professional and personal demands of the work. The stance must be proactive rather than reactive. Waiting for nurses to signal their distress may be too late. As participants noted, nurses are not always good to themselves and they have high levels of self-expectations related to clinical competence and being "professional" even in very difficult circumstances—sentiments supported by sociologists who have studied nurses in their work environments (e.g., Chambliss, 1996; Jameton, 1995; Vachon, 2001).

Since epidemiological patterns predict increasing incidence of cancer, illness that may be more chronic given increasing duration of treatment options, care needs that are more complex in light of the combination of increasing age and other health concerns, human resources (nurses and other health care providers) and material resources will be stretched even more than they are currently (Cancer Statistics, 2002). Thus, it is incumbent upon those who are in positions of authority and responsible for resource allocation to address work-related needs in collaboration with the persons who are being asked to deliver care in a context of felt burgeoning need. Public awareness of growing resource needs and possible solutions is, in part, the responsibility of regional, provincial, and federal systems that support health care. The results of this study give only a glimpse into the nursing role in transitional cancer care, but the findings are like the "canary in the mine," deserving to be heard and reviewed in the context of the systems in which these nurses function.

Nursing Research

Given the small sample and the absence of voices of nurses who are either less experienced in transitional cancer care or would admit to feeling uncomfortable with discussion of end-of life issues, it is recommended that the study be replicated. Less "expert" nurses may be able to offer different insights about the nature of communication with persons in their care who are living with advancing disease, and what barriers they perceive to be significant to their reluctance for such communication. Exploration of the attempt to blend a peer-nominated voluntary process along with a self-selective voluntary process in the same study, may also be worthwhile, as this study was unable to successfully accomplish theoretical sampling as had been designed methodologically.

Replication in a setting such as community home care nurses or nurses in a community hospital setting who are not functioning in a "disease site specific" clinical organizational structure may also prove beneficial in ascertaining the transferability of these findings. Patterns of retention and recruitment in the various cancer care settings may also be worthy of analysis.

Replication is also suggested in settings where the experience of progressing chronic illness other than cancer. This research is important as the palliative care community is working hard to broaden accessibility and the understanding of appropriate palliative care referral. Themes identified as common to both may then lead to educational strategies that can be included in the study of transitional health care having to do with mortal time issues more generally. Theories of transition may also benefit from evaluation and development in such studies. Ethnographic research studies to better understand what the lived experience of care providers—nurses as well as professionals from other disciplines—is also recommended, particularly given the trends for people to live longer with chronic illness. Nurses play a key role in the collaborative care of such persons.

Research into the ethical decision making processes of nurses—especially in the context of hierarchical systems of care delivery—is essential. Tensions about the "when to," "how to," "who to," and "what to" say were clearly identified and described in the findings of this study, confirming complexities described in the literature review.

Why are there so few male nurses in cancer care? The question of a gendered work force bears further inquiry. And how does the absence of males—or conversely the predominance of female nurses—have impact on the expression of need from males and females receiving transitional cancer care? Exploration of these queries too may benefit care provision if implications are better understood.

Why was it that the findings indicated that some teams worked collaboratively even within clearly hierarchical systems, while others did not? All teams worked within the same organizational culture and structure at the macro level, yet at a micro level, they functioned quite differently. What was it about some areas where there were clearly collegial and respectful attitudes between physicians and nurses, or among peer nurses, while in other teams the centrality of focus on "turf," rather than patient and family needs, dominated? Interestingly, when other team members from other disciplines such as social work or speech therapy were mentioned in the transcripts, the comments were all positive in respect to working relationships. It was only in the nurse-nurse and nurse-physician relationships that there was identified tension. Would this be similar in other cancer care centers? Was it simply certain personality traits of the members of the team? Or were other more malleable factors such as a system of felt values contributing to the differences of work life and thus quality of patient care?

Even in teams where there was greater control over patient scheduling so that nurses could have influence on their own time management for patient interactions, there was still evidence of emotional vulnerability. In the face of witnessing such continuous levels of human suffering, the need to add to the body of knowledge of how to implement strategies for effective worker support was a compelling finding and an area for further study.

Both the catharthis and peer learning that were experienced by the participants in this study in the sharing of their stories were significant. The participants' own comments beg for additional study of story sharing as a medium for contributing to education and grief work. The collective findings offer much in the way of peer learning about approaches to care and in articulating for—and with—each other the dilemmas felt in the work. In the focus group settings I suspect I was not alone in experiencing heightened regard for the wisdom of these expert nurses. Collectively, the participants voiced that sharing with each other with greater regularity could benefit all of them.

The literature review and discussion about methodology reflected the frequent use of individual interviews to glean desired insight and knowledge. Perhaps this study adds further credence to the use of focus groups in nursing research, for the purposes of narrative analysis in understanding the nature of our work. In some outpatient cancer care settings much work is done in privacy. To learn to parse out the nature of the work in a supportive setting may add to self-understanding and maturing in the profession, thus contributing to quality care, work satisfaction, and nurse retention. Further study using narrative frameworks and focus groups is recommended.

Thorne and Paterson (2000) have drawn attention to the need for more studies with a longitudinal view rather than basing findings on single interviews with the participants. Their reference is in large part one connected with changes over time in patient perspectives of their experience with chronic illness. Their thinking stimulates two recommendations for consideration in light of this study. One is that the experiences of transitional care were explored in this study from the nursing perspective only. Studies combining the joint knowledge and insights of patients, nurses, families, and other care providers have the dimension of rigor from data triangulation. Some of the comparable studies in this project's literature review used such methodological approaches. Perhaps the study of both patient readiness from their own perspectives, combined with insights from other disciplines would be helpful to provide a more trustworthy view of the concept of readiness to discuss palliative care referral.

The second perspective drawn from Thorne and Paterson (2000) would be to use a longitudinal study following the progress of individual nurses and or a team of nurses to assess their personal and professional growth in providing transitional care. Follow-up questionnaires three months after a communication-education seminar was used in the study by Fallowfield, Saul and Gilligan (2001); but the recommendation here is that the study have much longer duration and perhaps be more intensive than by survey methodology. Researching attitudes about death and dying, shared decision making, communication strategies that invited disclosure of patient/family concerns along with exploration of times when the participating nurses found themselves blocking or distancing in their communication, review of learning opportunities that have led to improved expertise and confidence, and self-care strategies along with organizational support interventions, would be helpful in determining more about how nurses can be supportive and how they respond to being supported themselves in the act of caring for persons with cancer.

In conclusion, it is clear that there is much potential for broadening the research focus and knowledge of nurses as they accompany ILWPC and their families through mortal time.

Personal reflections

Why did I want to explore this difficult, thorny area of caring in cancer nursing? In addition to the reason given earlier in the chapter about mentoring and wanting to know how we can do that better and wanting to study what is important to teach about communicating in mortal time, I know how distressed I have felt as nurse and person when things did *not* go as well as I wanted to see them go for people who were suffering. Personal experiences of caring for and supporting both my mother and father-in-law and a close friend with ALS in the roles of family member, friend and nurse, have helped me to recognize and then acknowledge my own need to receive support in the role of care provider while sharing mortal time.

I have learned many things, a few of which I will describe here. In the past year as I watched the movie John Q, I was inexplicably overwhelmed with tears. Hidden, or buried grief from my days in Intensive Care Unit nursing in California and Tennessee over twenty years ago, where I had worked under less than ideal conditions, were brought close to the surface of consciousness. Perhaps the reading and research processes related to this study had also been preparing me for this catalyst event for returning to my spirit to heal areas of suffering from my own nursing experiences that I thought I had already "processed." I continue to learn that vigilant attention to grief work is essential for nurses exposed to death on a regular basis.

I have frequently recalled the day at the Mayo Clinic in Rochester that found me in a privileged place with a clinical nurse specialist and a couple who, with two children, had survived a grueling experience of the wife's bone marrow transplant. She was facing recurrence yet again. The poignancy of suffering felt in that hour-plus of listening to her story and the interjected perspectives of her husband (thank you E & M for that trust in a stranger) as they struggled with "next-step" decisions I will never forget, nor regret, despite the rawness of suffering that the memory and empathy felt evokes for me. Do tears get shed?

I have learned that the "work" in transitional cancer care and shared mortal time must not be demeaned simply by calling it "work"; but it *is* hard work that demands involving one's total personhood.

There is a fine line between being an expert with competence and awareness of appropriate boundaries of shared and expressed emotion in this sharing and witnessing mortal time, and allowing expression of our own personal grief that is felt in this sacred human and spiritual space. As a manager responsible for the environmental and cultural climate of cancer care provision, I have learned that nurses entering cancer care need to know clearly it is not a place for those who need step-by-step instruction; nor is it a place for those who dislike either the roller-coaster experiences of progressing illness or who wish not to be exposed to suffering. It is, however, a place of privilege, full of complexity and nuance, of discovery of both self and the marvels of the resiliency of the human spirit. It is a place for those who have tenderness and hardiness as part of their personality. It is a place for those who love to hear and be partners in the creations of life story.

I have learned how much I appreciate the use of narrative in learning and mentoring others. Nursing cannot be without this significant medium for professional growth. By its very nature of connectedness, every encounter we have with others in the processes of caring is imbued with our moral agency. The values of our profession need to be consistently pre-eminent and the sharing of stories used to help us explore and clarify the depths of their meaning.

I have learned through dwelling with this data to appreciate and understand more of *my* personal limitations in trying to fathom the mysteries of death and the journey that takes some of us there through caring for others who live with the personal knowledge of progressing cancer. The importance of my own faith to my personhood and therapeutic self as I continue to work at understanding who I am and how my interactions with others affects them, has been brought into better focus. As Frank (1995) points out, our personhood is all we have to bring to the therapeutic relationship.

Conclusion

In summary, transitional cancer care could be described aptly as a place of ambiguity. Rather than trying to simplify a phenomenon that deserves to be honoured as complex because it is as unique as the individuals that enter "mortal time" together, we should celebrate—rather than feel overwhelmed by—the ambiguity. Such ambiguity reminds us that much suffering—a strong theme of many transitional cancer stories—"does not lend itself to fixing" (Frank,1992). Indeed, ambiguity, mystery, and uncertainty foster the very reflection and reflexivity that must prevail in respectful professional and personal experiences of "mortal time." The complexity of knowing just how and when to "do the right thing" challenges us to be discerning, to examine our assumptions, our motives, and our ethical and moral agency in order that individuals and their social families are truly "understood and not just known about" (Gustafson, 1974).

We must continue to learn more about this area of caring human interaction within the realm of health care provision, while respecting that there will always be aspects of living while dying that remain beyond our intellectual grasp. The absence of wooden, inflexible rules of practice calls us to reflect on the matrix of contextual and relational issues that both challenge us, yet add to the privilege—as well as pain—of mortal time.

We are called upon to be vigilant and discerning regarding the social structuring of care environments which have potential to detract from the respectful support of others' storying, as well as our own. We are also called to accountability in the way in which we use language and other communication skills; education of self and others to improve our sensitivity and wisdom in this area of practice is an ongoing responsibility. Nurses are in a pivotal place to shape solutions where there are barriers, and to continue to foster respectful and dignified support of persons moving towards death. It is an experience of whole personhood and community.

Transitional cancer care is a place where nurses are challenged to be creative, to open spaces for new stories, to articulate in compassionate and clear voices—for a society that is death-denying—the many ways in which nurses contribute to the narratives of "doing the right thing—right" in the experience of "mortal time."

APPENDIX A. INTERVIEW GUIDE: SAMPLE QUESTIONS

1. Are there formal criteria used in your work setting for enrolling patients in palliative/ hospice care? If so, what are they?

2. Do you find that patients have their own sense of "readiness," or "preparedness" to deal with talk of their awareness of dying? Can you provide me with some of your experiences in this regard?

3. What indicators do you use to determine a patient's readiness for palliative care?

4. How do you make decisions regarding talking with patients about palliative care?

5. What barriers or constraints do you encounter in making such decisions?

6. Please tell me the story of a time when you felt a patient experienced successful transition to palliative care.

7. What factors do you think were influential?

8. Please tell me a story of a time when things did not go well.

9. What factors do you think were influential in this situation?

10. What factors do you believe determine if and when patients will enter into discussions about palliative care? (In other words, how does it all "happen"?)

11. What, for you, causes feelings of discomfort, hesitancy, or anxiety about the process?

12. a) Do you broach conversations about end-of-life with patients and/or family members? How is this done? Are your experiences positive/or negative to date?

    b) What topics are touched on in conversations about end-of-life with patients (and/or family members)?

13. Do you ever confirm with the patient (and/or family) whether the conversation was satisfying/meaningful to them?

14. If so, how do you do this?

15. What are the most satisfying consequences of having facilitated a "good" patient transition to palliative care?

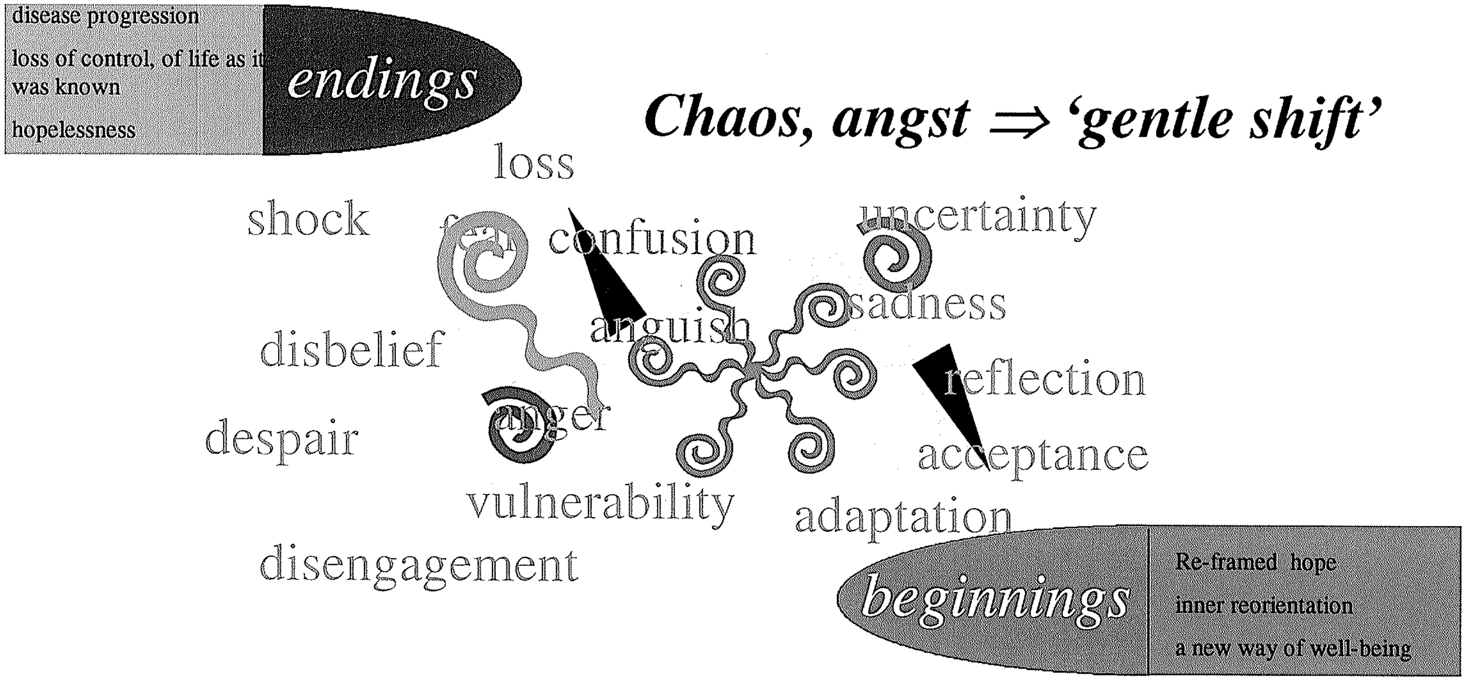
[*The last question will only be broached if this topic has not been described in the process of other response/information provided.*]

16. How do you see physicians involved in the process of transitional care? How do you see the role of the nurse integrating with the role of the physician in facilitating transition for patients?

APPENDIX B. MODEL OF TRANSITION: THE PERSPECTIVE OF THE INDIVIDUAL LIVING WITH PROGRESSING CANCER (ILWPC)

Transition:

living the awareness of "mortal time"



disease progression

loss of control, of life as it was known

hopelessness

endings

Chaos, angst ⇒ 'gentle shift'

loss

shock

fear

confusion

uncertainty

anguish

sadness

disbelief

reflection

anger

despair

acceptance

vulnerability

adaptation

disengagement

beginnings

Re-framed hope

inner reorientation

a new way of well-being

Inspired by Brennan, 2001; Bridges, 1980; Clarke-Steffen, 1993; Gregory & Russell, 1999; Reimer &Davies, 1991; Schumacher & Meleis, 1994; Mayer, 1998; McQuellon & Cowan, 2000; Tefs, 2002; Read, 2003

APPENDIX C. LETTER OF INTRODUCTION AND REQUEST FOR ACCESS

[University of Manitoba letterhead]

February 1, 2002

Ms. Vivian Painter,
Provincial Director, Patient Services
CancerCare Manitoba,
675 McDermot Avenue
Winnipeg, MB R3E 0V9

Dear Ms. Painter:

As you are aware, I am currently a student in the Master of Nursing program at the University of Manitoba. My thesis work in this program is entitled: "The nursing role in transitional cancer care: toward evidence-based understanding." I am seeking access to registered nurses from within CancerCare Manitoba as participants. I would be most appreciative of any assistance that you may be able to provide in order to facilitate the implementation of the research. The focus of the study is one which I believe has significance in several ways; but the pivotal hope is that a difference can be made in the care of individuals who are living with advancing cancer and are in need of timely referral to palliative care supportive services.

There is the possibility that this study will be replicated at the Mayo Clinic, Cancer Center and Quality of Life Program, in Rochester, MN., an outcome of the Summer Research Institute (a shared project of the Manitoba Nursing Research Institute, Faculty of Nursing, University of Manitoba, and Mayo Clinic). Grant proposal funding is being pursued for that purpose. If obtained, the CancerCare Manitoba portion will be Site 1 and the Mayo Clinic, Site 2, of a larger study.

I have been in touch with Natalia Eyolfson, Secretary for the Resource Impact Committee and have completed the required forms for Dr. Olweny, Chair, and the Committee's review. (The submitted version of my project proposal is an abridged format. Should you desire a complete copy I would be more than happy to send that to you as well.) As an external researcher I understand I need an internal study sponsor, and Karen Fletcher, Director of Nursing, has kindly agreed to be my sponsor for this project.

Please feel free to let me know if you have any concerns. Your support thus far for the Summer Research Institute and in progress with the project has been greatly appreciated. I look forward to hearing from you.

Yours sincerely,

Laurie Read
58 Lumsden Avenue
Winnipeg, MB, R2Y 0J7
837-3425; umreadlr@cc.umanitoba.ca

cc. Karen Fletcher, Director of Nursing, CancerCare Manitoba

Thesis Committee:
David Gregory, RN, Ph.D., Chair, Faculty of Nursing, University of Manitoba, (204)

Susan McClement, RN, Ph.D., Internal Member
Janice Mulder, MD, External Member

APPENDIX D. SUMMARY DESCRIPTION OF STUDY TO ACCOMPANY LETTERS OF INTRODUCTION

With growing commitment to improved care of individuals with progressive life-threatening illness, the profession of nursing is challenged to provide a better understanding, grounded in reliable research, of its role in caring for individuals whose treatment is no longer focused on cure.

There is already much evidence that the transition for patients who are entering into palliative care is complex from many perspectives. There is also a growing body of evidence to show that quality of nursing interventions affects patient quality of life. What has not been well researched to this point is the opportunity for nursing in the outpatient setting (increasingly the context of cancer care) to facilitate patient transition and care continuity through timely identification of patient readiness for discussion about palliative care.

The specific purpose of this study is to explore, in the outpatient cancer care setting, how and when nurses are able to pick up on cues of patient readiness to talk about palliative care and related issues as they facilitate transition for patients from curative treatment to palliative care.

An exploratory, qualitative study using person-centered interviewing of a sample of 10 peer-designated "expert nurses," plus two focus groups of 6-10 nurses—one of "experts," the other of self-selected proficiency levels (competent, proficient or expert according to Benner's (1984) criteria)—is the research design being used. This methodology has been chosen because it will reveal how registered nurses work with patients and families who transition from curative cancer care to palliative care. Participating nurses will have opportunity to provide feedback about whether or not the summary of the findings reflect their experiences. Themes that emerge from the findings will be summarized and reported on, with nurse participants and the supporting institutions receiving a copy.

The potential significance of the study is that it will seek to generate findings that will contribute to enhanced understanding of palliative care, for patients and their families through timely access to informational supports and symptom management that addresses relief of physical, psycho-social, and spiritual suffering. Further benefits could possibly include improved understanding of: current practices of cancer care nursing and the phenomenon of transitional care; ways to enhance both the mentoring of newer nurses to the field of cancer care, as well as other aspects of nursing education and research related to quality of life and quality care; areas of concern for cancer care nurses who are vulnerable to moral distress and caregiver 'burn-out' because of the nature of their work; and finally, community health because grief and other end-of-life issues are handled in a timely, sensitive, and patient-centered manner.

APPENDIX E. PEER-NOMINATION PROCESS

Peer nomination disclaimer

Project Title: ***The nursing role in transitional cancer care: toward evidence-based understanding***

Investigator: Laurie Read, R.N., B.Sc.N., MN student

***Purpose of the study*:**

The purpose of this Master of Nursing thesis project is to develop a better understanding of transitional cancer care (i.e., care during patient progression from curative care to palliative care) in the outpatient care setting, especially from the perspective of cancer care nurses. For example, how and when do nurses enter into discussions about palliative care and other related issues as patients' illness progresses to advanced stages?

In other studies, it has been helpful to have nurses choose representatives from among their peer group that can best relate to the issue being studied. Patricia Benner refers to such nurses as *experts* in their field, characterized by certain skills and abilities that reflect an *exemplary* quality to their practice. You are being asked to voluntarily give your opinion about the statements/scenarios on the attached form. That is the purpose of the process of peer nomination of some expert nurses in your clinical area as described below:

- You will not write your name on this form to identify it as your own.
- You may choose not to respond to one or all of the paragraphs if you so desire.
- Whatever you decide, your employment in this institution will not be affected in any way.
- Any questions you may have about the study will be answered and you may withdraw from this part of the study at any time.
- There are no known risks to you should you decide to complete this form.
- There are no immediate benefits to you for participating in this study.
- However, it is hoped that findings from this project will help nurses to learn more about the ways in which they can help patients and families who are transitioning from curative to palliative care.
- Your willingness to complete this form and hand it in signifies that you have agreed to take part in the peer nomination portion of this study.
- This study has received the appropriate ethical approval.

Instructions:

- *Please read each paragraph of the attached three scenarios carefully, and indicate the name(s) of cancer care nurses you work with that best fit each description.*
- *The nurse must have had a minimum of two years of experience in adult cancer*

nursing (not necessarily in your current setting), and presently be involved in providing patient care.

- *You may write the names of up to three nurses for each paragraph.*
- *The same nurse may be named for more than one paragraph.*
- *You may name yourself if you feel it is appropriate.*
- *Please submit the completed form in the envelope provided, seal and send it to the Nursing Department, c/o Liz Peetsma, who will be collecting the envelopes for Laurie Read, who will be picking them up on* ***March 15, 2002****.*

PEER NOMINATION FORM: *Scenarios of experts at work*

Scenario A: *'getting the whole picture'*

The following nurse seems to have real expertise in grasping the situation for patients with advanced cancer who are transitioning from curative to palliative care, and frequently will actively seek out the patient's understanding of the "whole picture." S/he realizes that there is little that can be done to prolong the life of this patient, but maintains a vision of what is possible when it comes to providing comfort and contributing to quality of life, even with the awareness of approaching death. This nurse helps the patient maintain a sense of self-esteem and dignity, and seems to know intuitively how to choose appropriate times and words for discussion of issues related to palliative care. S/he is someone you might seek out to contribute to the care of patients whose circumstances are made even more complex because of the impact of advancing illness and personal coping factors.

Name of nurse: *(please print)*

____

Name of nurse: *(please print)*

____

Name of nurse: *(please print)*

____

Scenario B: *'having intuitive sense'*

This nurse is especially sensitive to the needs of the families of patients whose cancer is advancing to the degree that it is evident treatment goals require discussion/revision. S/he promotes an environment in which the participation of the family is encouraged, if that is their wish. This nurse recognizes that many relatives and care-giving friends feel a need to be helpful to the dying person. Sometimes this is encouraged not just in response to a situation. This nurse actually plans ahead in anticipation of the need to foster and guide relevant and meaningful discussion, laying the groundwork so that palliative care is considered in a timely manner. Because s/he appears to have an intuitive grasp of the needs of dying patients and their families, s/he is able to provide care in the latter stage of life in a truly remarkable way.

Name of nurse: *(please print)*

____

Name of nurse: *(please print)*

____

Name of nurse: *(please print)*

Scenario C: *'zeroing in with skill and sensitivity'*

This nurse is an excellent communicator. S/he promotes clear, empathetic communication between individuals living with the knowledge that their cancer is rapidly progressing, their family members, and other health care team members. This nurse is sensitive to the needs of both patient and family to talk about their impending loss and what it means to them. S/he can respond effectively to the fear and anger patients and their family members may express. S/he seems to be able to zero in on an accurate assessment of their concerns, whether they are physical, psychosocial, emotional or spiritual in nature. She is able to teach and provide information to empower patients and families with admirable skill. And, you have a sense that s/he knows how to affirm the unique meanings of a dying individual's life experience in a genuine, caring way because there is such responsiveness in patients and families to his/her interactions with them.

Name of nurse: *(please print)*

Name of nurse: *(please print)*

Name of nurse: *(please print)*

Thank you for your commitment and time in completing this form.

Other relevant information:

The study is being done as part of the work required for the Master of Nursing at the University of Manitoba. The findings from the study will be available to you and your participating organization. Findings may be published, but participant names will not be used, nor will CancerCare Manitoba be specifically identified. The researcher or supporting advisor will be available to you throughout the study to address any concerns or questions (contact information below). If you choose to participate, your assistance is appreciated. If you choose not to participate, your decision will be respected.

The study has been approved by the Education/ Nursing Research Ethics Board (ENREB), University of Manitoba, and the Resource Impact Committee of CancerCare Manitoba. Should you have any questions or concerns regarding procedures of this research project please contact the Human Ethics Secretariat at (204) 474-7122.

Contact:
Laurie Read, RN, BScN, MN student

Thesis Committee:
David Gregory, RN, Ph.D., Chair; Faculty of Nursing, University of Manitoba,

Susan McClement, RN, Ph.D., Internal Member, Faculty of Nursing
Janice Mulder, B.Sc.(Pharm), M.D., External Member

APPENDIX F. SELF-SELECTION FORM FOR VOLUNTEER FOCUS GROUP INTERVIEWEES

Part I: Information sheet and disclaimer

(All nurses will be invited to complete this form, according to their willingness to do so)

Project Title: ***The nursing role in transitional cancer care: toward evidence-based understanding***
Investigator: Laurie Read, R.N., B.Sc.N., MN student

Purpose of the study:

The purpose of this study is to develop a better understanding of transitional cancer care in the outpatient care setting from the perspective of cancer care nurses. For example, how and when do nurses enter into discussion about palliative care and other related issues as patients' illness progresses to advanced stages?

In this study, the researcher wants to involve, in two focus groups, cancer care nurses at several levels of clinical practice proficiency. Sometimes nurses may want to develop even more expertise with certain aspects of cancer care, and their questions, concerns, insights, and stories can provide valuable probing into the issue itself or about the practice of nurses who are recognized as exemplary in those areas of care. Thus, one focus group will be composed of nurses who are peer-nominated as "experts," the other of nurses from proficiency levels III-IV as described below, and as determined by the nurses' own self-awareness.

Background for your decision to participate in a focus group discussion of the above topic:

It would seem that some nurses can broach end-of-life issues with exceptional sensitivity to timing and patient need. These are those individuals we often regard as exceptional or having expertise and seemingly intuitive dimensions to the manner in which they care for others. Others are less comfortable, and find themselves hesitant to approach the topic with patient and families. Some nurses may feel they lack confidence, or experience in talking about end-of-life issues, and would like to learn more about how and when to approach patients who are transitioning in their advancing cancer. Patricia Benner (a nurse theorist who has focused on clinical practice, the nature of nurse caring, its related stress, and how nurses gain expertise), has described five "levels of nursing proficiency." The early stages are I- novice, and II- advanced beginner. The ongoing stages pertinent to this project are described more fully as follows:

III. Competent:
  - Typically been in practice 2-3 years
  - Can rely on long range plans to set priorities
  - lacks speed & efficiency of nurse at proficient level; but, able to feel mastery, copes well with many contingencies

IV. Proficient:
  - Able to take in *whole* situation, not just aspects of it
  - Less labored decision making, considers fewer options, able to quickly priorize

- Hones in on the accurate problem area

V. Expert:

- No longer needs to rely on rules or guidelines to connect understanding of the whole situation to an appropriate action
- Enormous background of experience
- Has intuitive grasp of situation; zeros in on accurate area of problem without wasteful consideration of unfruitful possibilities/options

You are being asked to voluntarily give your opinion about the statements on the attached form. The purpose of the self-selection process, outlined below, is to assist in recruiting willing participants for the focus group phase of the study:

- You may choose not to respond to one or all of the questions if you so desire.
- Whatever you decide, your employment in this institution will not be affected in any way.
- Any questions you may have about the study will be answered and you may withdraw from this part of the study at any time. (See contact information below).
- There are no known risks to you should you decide to complete this form.
- There are no immediate benefits to you for participating in this study.
- However, it is hoped that the findings from this project will help nurses to learn more about the ways in which they can help patients and families who are transitioning from curative to palliative care.
- Your willingness to complete this form and hand it in signifies that you have agreed to take part in the self-selection portion for consideration in the formation of the 2 focus groups as part of this study.

Acknowledgements:

Benner, P., & Wrubel, P. (1982). Skilled clinical knowledge: the value of perceptual awareness. Nurse Educator(May-June), 11-17.

McClement, S. E., & Degner, L. F. (1995). Expert nursing behaviors in care of the dying adult in the intensive care unit. Heart & Lung, 24(5), 408-419.

Raudonis, B. M. (1993). The meaning and impact of empathic relationships in hospice nursing. Cancer Nursing, 16(4), 304-309.

Other relevant information:

The study is being done as part of the work required for the Master of Nursing at the University of Manitoba. The findings from the study will be available to you and your participating organization. Findings may be published, but participant names will not be used, nor will CancerCare Manitoba be specifically identified. The researcher or supporting advisor will be available to you throughout the study to address any concerns or questions (contact information below). If you choose to participate, your assistance is appreciated. If you choose not to participate, your decision will be respected.

The study has been approved by the Education/ Nursing Research Ethics Board

(ENREB), University of Manitoba, and the Resource Impact Committee of CancerCare Manitoba. Should you have any questions or concerns regarding this research project please contact the Human Ethics Secretariat a

Contact: Laurie Read

Thesis Committee:

David Gregory, RN, Ph.D., Chair; Faculty of Nursing, University of Manitoba
Susan McClement, RN, Ph.D., Internal Member, Faculty of Nursing
Janice Mulder, B.Sc.(Pharm), M.D., External Member

APPENDIX F (CONTINUED)

Self-selection form-Part II questionnaire

Some questions:

Please place a checkmark in front of the most appropriate answer for you.

1. Given Benner's levels of proficiency as outlined above, what level would you say best describes your current practice?
   ☐ competent ☐ proficient ☐ expert
2. Do you ever have times where you have conversations with patients that focus on introducing the idea of palliative care/hospice care or the meaning of the patient's advancing illness, or of referring patients to information about palliative/hospice care?
   ☐ yes ☐ no (If no, please go to Question 5.)
3. If yes, how frequently?
   ☐ regularly ☐ on occasion ☐ infrequently
4. Would you be willing to share more about those conversations in a focus group of six to ten cancer care nurses, along with a group moderator and nurse researcher?
   ☐ yes ☐ no
5. If you answered "no" to Question 2, do you think that such conversations should be a part of the nursing role in transitional cancer care?
   ☐ yes ☐ no

If you said "yes" to Question 4, and are willing to participate, would you prefer that the group meet:

☐ immediately following work,
☐ other preference (*please indicate when)*

____

If you want to know more about the focus group meeting, please leave the following information so that you can be contacted:

Name(printed): ____________________

Phone: _______________________

*email:*____________________________________

Or, if you prefer, you may **contact** Laurie Read

Please place this completed form in the envelope provided, and send to the Nursing Department c/o Liz Peetsma who will be collecting them for Laurie Read. The deadline for submission is ***March 15, 2002.***

Thank you for your feedback.

APPENDIX G. CONSENT FORM: INDIVIDUAL INTERVIEW

[*to be printed on University of Manitoba letterhead*]

Project Title: **The nursing role in transitional cancer care: toward evidence-based understanding**

Investigator: Laurie Read, RN, BScN, MN student

Individual Interview Participant Consent
Part I: Information and overview

Purpose of the study:
The purpose of the study is to develop a better understanding of transitional cancer care in the outpatient care setting, especially from the perspective of cancer care nurses. For example, how and when do such nurses enter into discussion about palliative care and other related issues as patients' illness progresses to advanced stages? The study has the potential to increase our understanding of the nursing role in determining patient readiness or preparedness for such discussions, thus potentially enhancing palliative care intervention in a timely and sensitive manner.

Participation:

You have been selected through the peer nomination process to participate in this study by way of an interview with the researcher. Participation is entirely voluntary, and at any time you may decide not to answer a question, or to withdraw from the study, without consequence or prejudice, simply by telling/notifying the researcher.

Information obtained from you or about you, during this study, or which could reflect your identity, will be kept confidential by the researcher. The researcher will be your contact and will be available during the study should you have any questions or concerns. Administrators, clinical supervisors/managers, and any other persons involved with your organization will not have access to your taped interviews or any other information that could potentially identify you as a source.

Description of Process:

You are being asked to participate in one interview which will take place either in your work setting or at another location of your choice, and at a time that is convenient for you. You will be given some sample questions ahead of the interview prior to your participation in order to help you understand the direction or intent of the interview. However, these questions are only a framework, and you will be assured of the freedom to expand on their core intent as you feel the sharing of that information, your experience and expertise may be helpful to the study. You will also be asked to complete a Participant Information Form which asks for some personal and professional information. This information will contribute to data by providing an overall profile of the participants.

Interviews will be taped with your permission, and the tape will be transcribed word for word. This is done in order to assist the interviewer's recall, and to preserve the integrity of your comments in detail. (The researcher may occasionally make written jottings as well to assist with recall of contextual data.)Your audiotape will be coded so that when the data is reviewed your name will not be on the transcription. The list of participant names and codes will be kept in a locked location, apart from the transcripts. Within several weeks you will be given a summary of the interview and, again with your consent, you will be asked to confirm with the interviewer, by phone contact, whether or not the report accurately reflects your experiences. You will also be given an opportunity to provide any additional information at this time. The information provided by all of the individuals who are interviewed will be summarized and provide a basis for some of the focus group discussion; however, no one individual's name will be directly linked with any data that is provided.

Duration of participant's involvement:

Initial interview:	*approximately 60-90 minutes*
Phone follow-up, confirmation of interview summary:	variable according to participant; approximately 5-15 minutes

Possible risks, discomforts or inconveniences:

There are no expected risks from participating in this study. You may refuse to answer any questions that make you feel uncomfortable and ask the researcher to terminate the interview at any time, without consequence or prejudice. All identifying information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the researcher.

Benefits the participant may receive:

It is hoped that the findings from this project will help nurses learn more about the ways in which they can help patients and families who are transitioning from curative to palliative care. You yourself may not benefit directly or immediately from participation in this interview, but some value may be gained from the experience of reflecting on your caring relationship with patients who are experiencing transition to palliative care.

Other relevant information:

The study is being done as part of the work required for the Master of Nursing at the University of Manitoba. The findings from the study will be available to you and your participating organization. Findings may be published, but your name will not be used, nor will your organization be specifically identified. The researcher or supporting advisor will be available to you throughout the study to address any concerns or questions (contact information below). If you choose to participate, your assistance is appreciated. If you choose to withdraw from the study, your decision will be respected.

The study has been approved by the Education/Nursing Research Ethics Board (ENREB), University of Manitoba, and the Resource Impact Committee of CancerCare Manitoba. Should you have any questions or concerns regarding this research project please contact the Human Ethics Secretariat

Participant initials to indicate that the above portion of the consent has been read: ________
(Please continue to Part II, to sign consent form.)

Contact: Laurie Read, RN, BScN, MN student

Thesis Committee:
David Gregory, RN, Ph.D., Chair; Faculty of Nursing, University of Manitoba,
Susan McClement, RN, Ph.D., Internal Member, Faculty of Nursing,
Janice Mulder, B.Sc.(Pharm), M.D., External Member,

[*to be printed on University of Manitoba letterhead*]

INDIVIDUAL INTERVIEW PARTICIPANT CONSENT—PART II: SIGNATURE PAGE

<u>Project Title</u>: The nursing role in transitional cancer care: toward evidence-based understanding

I, ____________________________________, the undersigned, agree to participate in the study: "The nursing role in transitional cancer care: toward evidence-based understanding."

I have read the explanation of the above project on the attached sheets. I have had all my questions answered and know that I can ask any future questions at any time by contacting the researcher at the number below. I have been given a written explanation of the project, and I understand what is involved in my participation. I realize that in addition to the researcher, her transcriber, and thesis committee will have access to the data; but transcripts will not identify any participants by name; an anonymous code will be assigned to each transcript and be known only to the researcher. I realize participation is voluntary and there is no guarantee that I will benefit from my involvement. I understand that other than the time it takes to participate in this study, there are no known risks to me for taking part in this project. I am aware that I may withdraw from the study at any time, without consequence or prejudice, simply by telling the researcher. A copy of this consent form will be given to me to keep for my own records. My signature below indicates:

- my willingness to participate
- my willingness to meet with the interviewer/researcher in a place and time of my choosing (due regard being paid to safety, confidentiality, and comfort)
- my agreement to have the interview audiotaped
- my awareness that the researcher may also make some written notations during the interview
- my agreement to complete the one-page Participant Information Form
- my agreement to provide feedback to the interviewer/researcher about the accuracy of the transcript of the interview
- my agreement to have my data, unidentified as mine, included in the collective summary that will then provide some framework to questions that may be discussed in the study's focus group phase.

I would like to receive a copy of the study findings. Yes ☐ No ☐

Name of participant: ________________________________(Please print)

Signature of participant: ______________________________ Date: ______________

To be signed by interviewer/researcher

To the best of my ability I have fully explained the nature of this research study. I have invited questions, and where necessary provided answers and responses to expressed concerns. I believe the participant understands the implications and voluntary nature of the study. The participant is aware that I may be reached at the contacts identified on the information sheet and that if they have any questions about procedure they may contact the Human Ethics Secretariat at (204) 474-7122.

Signature of the interviewer: ___________________________ Date: ______________

APPENDIX H. CONSENT FORM: FOCUS GROUP INTERVIEW

Project Title: The nursing role in transitional cancer care: toward evidence-based understanding

Principal investigator: Laurie Read, RN, BScN, MN student

Focus Group Participant Consent Form

Part I: Information and overview

Purpose of the study:

The purpose of the study is to develop a better understanding of registered nurses' experience in transitional cancer care in the outpatient care setting. The study has the potential to increase our understanding of the nursing role in determining patient readiness or preparedness for such discussion, thus enhancing palliative care intervention in a timely and sensitive manner.

You have volunteered to let your name stand, and have completed the self-selection form to ensure that you meet the study criteria. Based on your eligibility, you have been selected to participate in the focus group phase of the study. Participation is entirely voluntary, and at any time you may decide not to participate or to withdraw from the study without consequence or prejudice.

Information obtained from you or about you, during this study, or which could reflect your identity, will be kept confidential by the researcher, and the group moderator. The researcher, Laurie Read, will be your contact and will be available during the study should you have any questions or concerns. Administrators, clinical supervisors/managers, or any other persons involved with your organization will not have access to your contributions to the taped focus group interview or any other information that could potentially identify you as a source.

Description of Process:

You are being asked to participate in one focus group meeting with 5-9 other cancer care nurses. The focus group interview will take place in a location either in your work setting or at another time and location that is convenient for you and the other participants. Refreshments will be provided. Should you require assistance with transportation or child care costs in order to participate, those arrangements will be made in accordance with your wishes. An experienced group facilitator/moderator (Ms. Elaine Mordoch, RN, MN) will be present to assist the researcher. You will be asked to treat confidentially all matters discussed in the focus group.

You will be given some sample questions prior to the focus group meeting in order to help you understand the direction or intent of the discussion. However, these questions are only a framework; you are not under obligation to read them ahead of time, and you will be assured of the freedom to expand on their core intent as you and the group members may want to share additional information. Your experience and ideas will be helpful to the study. You will also be asked to complete a Participant Information Form which asks for some personal and professional information. This information will contribute to data by providing an overall profile of the participants.

The session will be audiotaped with the written consent of the participants, and the audiotape will be transcribed word for word. This is done in order to assist the researcher and group facilitator's recall, and to preserve the integrity of your comments in detail. (The researcher and/or moderator may occasionally make written jottings as well (e.g., to assist with recall of contextual data, or to jog her memory)). The audiotape will be coded so that when the data is transcribed, identification of participants will be eradicated and codes or pseudonyms inserted so no names will be on the transcription. The list of participant names and codes will be kept in a locked location, apart from the transcripts. Within a period of several weeks you will be given a summary of the interview and, again with your consent, you will be asked to confirm with the researcher whether or not the report accurately reflects your experiences as expressed within the group setting. You will also be given an opportunity to provide any additional information at this time. Only the researcher, group moderator, transcriber, and thesis committee will have access to the data. All matters discussed in the focus group will remain confidential.

Duration of participant's involvement:

Initial focus group meeting: approximately 60- 90 minutes
Follow-up by phone to confirm accuracy of summary: variable according to participant; approximately 5-15minutes

Possible risks, discomforts or inconveniences:
There are no expected risks from participating in this study. You may refuse to answer

any questions that make you feel uncomfortable and ask to terminate your participation at any time, without consequence or prejudice, simply by telling the researcher. If you choose to participate, your assistance is appreciated. If you choose to withdraw, your decision will be respected. All identifying information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the researcher.

Benefits the participant may receive:
It is hoped that the findings from this project will help nurses learn more about the ways in which they can help patients and families who are transitioning from curative to palliative care. You yourself may not benefit directly or immediately from participation in the focus group, but some value may be gained from the experience of reflecting on your caring relationship with patients who are experiencing transition to palliative care.

Other relevant information:
This study is being done as part of the requirements for the Master of Nursing, University of Manitoba. Ethical approval has been received from the University of Manitoba, Research Ethics Board, and approval for access received from the Resource Impact Committee of CancerCare Manitoba. Should you have any questions or concerns regarding this research project please contact the Human Ethics Secretariat

The findings from the study will be available to you and your participating organization. Findings may be published, but neither you nor your organization will be identified by name. The researcher or supporting advisor will be available to you throughout the study to address any concerns or questions.

Contact: Laurie Read, RN, BScN, MN student;

Thesis Committee:
David Gregory, RN, Ph.D., Chair, Faculty of Nursing, University of Manitoba,
Susan McClement, RN, Ph.D., Internal Member,
Janice Mulder, MD, External Member,

Participant initials to indicate that this information sheet has been read: ________
(Please continue to Part II, the Consent signature page.)

[University of Manitoba Letterhead]

Focus Group Interview Participant Consent

Part II: Signature Page

I, ____________________________________, the undersigned, agree to participate in the study: "The nursing role in transitional cancer care: toward evidence-based understanding."

I have been given a written explanation of the project, and I understand what is involved in my participation. I have had all my questions answered and know that I can ask any future questions at any time by contacting the researcher at the number below. I realize that in addition to the researcher, her transcriber, and thesis committee will have access to the data, but transcripts will not identify any participants by name; an anonymous code will be assigned to each transcript and be known only to the researcher. I realize participation is voluntary, that I may withdraw at any time, or refrain from answering whatever questions I may prefer to omit, without consequence or prejudice, simply by telling the researcher. I realize that other than the time it takes to participate in the study, there are no known risks to me for taking part in this project; nor is there guarantee that I will benefit directly or immediately from my involvement. A copy of this consent form will be given to me to keep for my own records. My signature below indicates:

- my willingness to participate in a focus group
- my willingness to meet with the researcher, the moderator-facilitator and the rest of the group in a place and time that has been mutually agreed upon (due regard being paid to safety, confidentiality, comfort and group consensus)
- my agreement to have the group interview audiotaped
- my awareness that the researcher may do some minimal note writing also during the group interview
- my agreement to complete the one-page Participant Information Form
- my willingness to receive a follow-up phone call to confirm accuracy of the summary of the focus group meeting
- my understanding that the group proceedings will be kept in confidence, and that I too will keep them in confidence.

I would like to receive a copy of the study findings. Yes ☐ No ☐

Name of participant: ______________________________ (Please print)

Signature of participant: ____________________________ Date: _______________

<u>To be signed by interviewer/researcher</u>

To the best of my ability I have fully explained the nature of this research study. I have invited questions, and where necessary provided answers and responses to expressed concerns. I believe the participant understands the implications and voluntary nature of the study. The participant is aware that I may be reached at the contacts identified below, or that if there is any concern regarding procedure that the Human Ethics Secretariat at (204) 474-7122 may be contacted.

Signature of the interviewer: ____________________________Date: ______________

APPENDIX I. PARTICIPANT INFORMATION FORM

Code Identification: ____________

Age: ☐ 20-29 ☐ 30-39 ☐ 40-49 ☐ 50-59 ☐ ≥ 60

Religion: (*If "none," or a religion not designated, please indicate under "other."*)

☐ Catholic ☐ Jewish ☐ Muslim ☐ Protestant ☐ Agnostic/ Atheist ☐ Other __________

Religiosity:

1	2	3	4	5
Religion is a highly important part of my life.				Religion is not important to me at all.

Ethnic/cultural group with which you identify yourself: _________________________

Formal nursing education:

☐ Diploma ☐ B.N./B.Sc.N. ☐ M.N. ☐ certificate________ ☐ other______

Years of experience as a registered nurse: _____________

Years of experience as a cancer nurse: ________________

Did your introduction to cancer nursing occur in your current workplace/ organization?

☐ Yes ☐ No

Comment if recent change(s) in your work environment that might help/detract/influence your nursing practice:

____

____

Have you experienced the death of someone close to you?

☐ Yes ☐ No

If yes, what was the person's relationship (what were the persons' relationships) to you? How long ago did the death occur?

____

____

____

Thank you for your assistance.

APPENDIX J: LETTER OF NOTIFICATION OF PEER NOMINATION

[University of Manitoba Letterhead]

[*Nurse's Name*]
CancerCare Manitoba,
Site [*McCharles or St. Boniface*]
675 McDermot Ave.
Winnipeg, MB
R3E 0V9

[Date]

Dear (*nurse's name*):

Congratulations. You have been nominated by your peers as being expert in your clinical practice of cancer care nursing, a worthy recognition. As such your peers have indicated their confidence in your ability to speak clearly about the practice of cancer nursing, particularly in relation to the experience of communicating with patients and families who are "transitioning" from acute cancer care to care that focuses on supportive, palliative care interventions.

Enclosed please find a copy of the information sheet and consent form that will inform you in detail about what your participation in this project would entail should you be willing to participate. If you decide to be interviewed, I would appreciate your call to indicate your willingness as soon as possible so that we can set up a time and place that is convenient for you. If you have any need for clarification, or have questions or concerns, please feel free to call or email me at the number/address below.

Your time and expertise are valued. Thank you for your consideration of contributing to this study.

Yours sincerely,

Laurie Read, BScN, RN,
M.N. Student

APPENDIX K: LETTER OF NOTIFICATION OF FOCUS GROUP PARTICIPATION

[University of Manitoba Letterhead]

[*Nurse's Name*]
CancerCare Manitoba,
Site [*McCharles or St. Boniface*]
675 McDermot Ave.
Winnipeg, MB
R3E 0V9

Date

Dear (*nurse's name*):

Thank you for indicating your interest in focus group participation for the project on transitional cancer care and determining patient readiness to speak about end-of-life care. Your observations and thoughts on the practice of cancer nursing, particularly in relation to the experience of communicating with patients and families who are "transitioning" from acute cancer care to care that focuses on supportive, palliative care interventions would be valued should you agree to participate.

Enclosed please find a copy of the information sheet and consent form that will inform you in detail about what your participation in this project would entail. If you decide to be interviewed within the focus group setting, I would appreciate your call to indicate your willingness as soon as possible so that we can set up a time and place that is convenient for you and the others who are also participating.
If you have any need for clarification, or have questions or concerns, please feel free to call or email me at the number/address below.

Your time and experience are valued. Thank you for your consideration of contributing to this study.

Yours sincerely,

Laurie Read, BScN, RN,
M.N. Student

APPENDIX L: STUDY TIMELINE

Proposal approval Chapters 1-3

November, 2001

Ethical review process

Submitted December, 2001; official approval received January 24, 2002.

Letters of request to participating institution

- January, 2001:Once ethical approval received, letters of introduction, explanation and summary of research proposal sent to CancerCare, Manitoba.
- Arrangements for staff meeting through Director of Nursing, Karen Fletcher, and Unit Managers (Julia Barley & Gloria Kirouac), as directed by Vice President, Patient Care Services, Vivian Painter, made in January, 2002.
- meeting arranged for February 5, 2002.
- Resource Impact Committee submission due February 13, 2002; reviewed by committee, and accepted on February 27, 2002.
- introduction meetings for staff arranged with Miriam Corne for March 1, 2002, 0800, MacCharles site, 4th floor boardroom;
- March 7, 2002, 0830, St. Boniface site in Oncology Administration Conference room
- Arrangements for transcriber, Kristen Harris confirmed
- Arrangements for focus group moderator: (initial contact with Elaine Mordoch made informally in December, 2001); once details with CCMB worked out, officially confirmed in February, 2002 re projected timeframe

Peer nomination process

Started March 1, 2002

- forms given to nominators (Staff RNs) at time of meeting
- screening of peer nomination forms; selection of nominees
- notification of successful candidates by email, and /or phone depending on their stated preference
- according to decision about participation, processes for informed consent to be worked out with participants; forms sent ahead of time for review, with signing of consent at time of interview.
- focus group membership determined also at this time, and letters of acknowledgement of participation provided

Individual Interviews

Started March 30,2002; completed May 7, 2002 (repeat interview since original tape malfunctioned)

Focus Groups

- Focus group 1:-April 29, 2002
- Focus group 2: May 8, 2002

Data transcription

Completed within days of each interview, read and corrected after matching with audiotape.
Original tapes and transcripts copied and stored according to ethics application.
Working copies for coding kept in separate binder.

Analyze Data

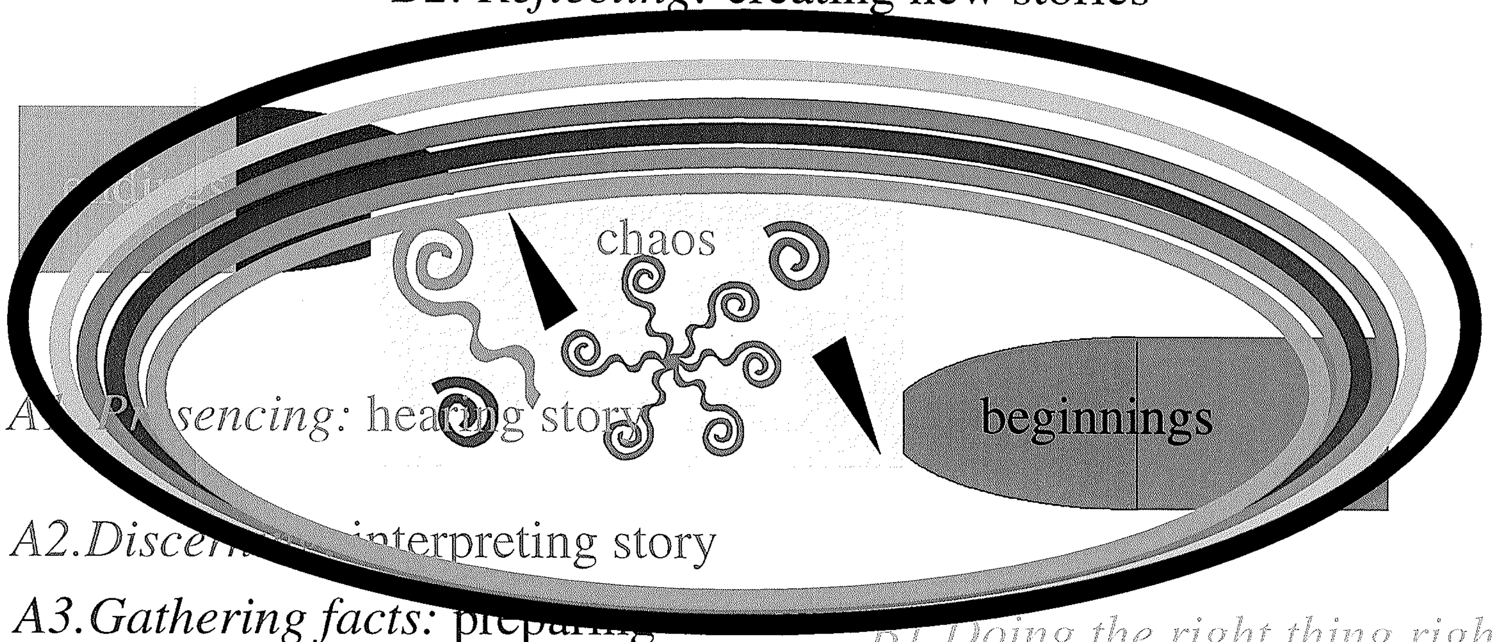
Started in April and initially completed by July; but fine-tuned over next 6 months

Writing of summary of findings:

- started in June, 2002, Completed in May 2003!
- approval by Chair
- Thesis defense: June 19, 2003
- Sending of results to participant nurses and their hosting facility once thesis complete
- Filing of document with Graduate Studies Department, July, 2003
- convocation in October, 2003

Transition: Sharing "mortal time"

B2. Reflecting: creating new stories



A1. Presencing: hearing story

A2. Discer… interpreting story

A3. Gathering facts: preparing
the way for storying

A4. Coming alongside: supporting the living of story

B1. Doing the right thing right:
supporting integrity of story

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