

**An Exploration of Oncology Nurses Experience of Providing Non-Curative
Care to Patients with Advanced Cancer**

by

Lisa Streeter
BN, University of Manitoba, 1997

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of the Requirements for the Degree of

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Supervisory Committee

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Dr. Marjorie McIntyre, School of Nursing
Supervisor

Dr. Carol McDonald, School of Nursing
Departmental Member

Abstract

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Dr. Marjorie McIntyre, School of Nursing

Supervisor

Dr. Carol McDonald, School of Nursing

Departmental Member

Although there is a growing movement to conceptualize palliative care as an integral part of comprehensive cancer care, access to coordinated palliative care services is often limited to end-of-life when efforts to control the disease have failed. Little was known about how this phenomenon is experienced in oncology nursing practice. A phenomenological approach was used to explore oncology nurses experience providing non-curative care in one of six outpatient cancer settings within an urban health region in Western Canada. Emerging understandings suggest that oncology nurses support patients' hopes for prolonged survival with non-curative treatment while revisiting treatment decisions in the context of witnessed suffering. In the context of mounting symptoms, oncology nurses strive to construct a 'safety net' of community supports to rescue patients from crisis. Inherent tensions within this experience are shaped by how cancer care and palliative care are understood, how treatment decisions are framed within their care team, and organizational constraints in the provision of services in the community. These understandings invite further discussion about strategies to support oncology nursing practice in the provision of non-curative care.

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Dedication

I would like to dedicate this work to the many oncology and palliative care nurses that I have had the privilege to work with and learn from throughout the course of my career. In particular, I would like to thank the participants of this study who so willingly shared their experience. Your commitment to quality patient care is inspiring.

Chapter 1

Non-Curative Care in Cancer Care: Evolving Understandings

Despite recent advances in cancer screening, diagnosis and treatment, approximately 40 – 45% of Canadians will develop cancer in their lifetime and one in four will die of advanced disease (Canadian Cancer Society, 2009a). The number of cancer deaths in Canada has been steadily increasing, largely due to a growing aging population. On average, 46% of people diagnosed with cancer die within five years of their cancer diagnosis (Canadian Cancer Society, 2010) and most people living with advanced cancer experience troubling physical and psychosocial symptoms during the course of their illness (Lindstone et al., 2003; Walsh, Donnelly, & Rybicki, 2000). The impact of living and dying with advanced cancer is significant, certainly at the personal level, but also at the societal level as more and more Canadians face a diagnosis of advanced cancer as the population ages (Canadian Cancer Society, 2010).

Health care providers are being challenged to meet the growing needs of patients and families living with advanced cancer within a health care system that has historically been structured to manage cancer and death as polar opposites of the cancer illness continuum. The specialties of medical oncology and palliative care each add a valuable dimension in the care of patients and families living with advanced cancer. In keeping with the traditions and historical evolution of each specialty, nurses in oncology practice have developed sophisticated knowledge of treatments used to modify and control cancer illness while palliative care providers have developed expertise in symptom management and having difficult discussions with patients and families in a time of emotional, physical, and existential crisis. As noted by Ahmedzai et al. (2004), the challenge in

developed countries where these specialties have developed in isolation of one another is in determining how to ensure that patients and families receive the best of both worlds, at all points in the cancer trajectory, while acknowledging the distinct skills of the health care professionals who care for them.

There is growing evidence to support the value of integration of holistic, blended palliative care / supportive care philosophies throughout a patient and family's cancer experience. Palliative care has been associated with better outcomes including: enhanced patient care (Higginson, et al., 2002; Higginson, et al., 2003), patient satisfaction (Rabow, Schanche, Petersen, Dibble, & McPhee, 2003), family caregiver satisfaction (Gelfman, Meier, & Morrison, 2008; Hearn & Higginson, 1998), help with understanding the diagnosis and prognosis (Ellershaw, Peat & Boys, 1995; Jack, Hillier, Williams, & Oldham, 2004), and improved symptom management (Hanks, et al., 2002; Thomas, Wilson & Sheps, 2006). Given the nature of the cancer experience – and the complex physical, emotional, spiritual, and practical implications of being diagnosed with advanced cancer, a blended approach that incorporates the knowledge and skills of both oncology and palliative care specialties is intuitively appropriate in ensuring that patients and families living with advanced cancer receive the treatment and support they require throughout the trajectory of their illness.

Although there is a growing movement to conceptualize palliative care as an integral part of comprehensive cancer care, the provision of existing services does not often reflect this vision (Carstairs, 2010). Locally, and in many parts of Canada, eligibility for enrolment to receive coordinated palliative care services is limited to include those with an identified prognosis of less than six months who have decided to

forgo further treatment with systemic chemotherapy. Arguably, this narrow construction of palliative care (made necessary by limitations in resources), perpetuates the artificial separation of palliative care and cancer care (Carstairs, 2010). Although it is widely recognized that people living with advanced cancer would benefit from a combined palliative / oncology approach throughout their illness, the majority receive palliative care through formal palliative care services late in the illness when attempts to cure or slow the progression of disease have failed (Carlson, Morrison, & Bradley, 2008; Carstairs, 2010; Gaudette, et al., 2002). Average length of stay in palliative care programs in Canada and the U.S. typically range from 30 to 45 days (Gaudette et al., 2002; Carlson et al., 2008). This is consistent with palliative care service utilization statistics locally (Lori Embleton, personal communication, June 1, 2010).

Throughout the course of my career I have had the privilege to practice nursing in 'both worlds' - first as an oncology nurse working in both the acute inpatient and outpatient care settings and later in my current role as a clinical nurse specialist within the urban regional palliative care program. I have personally struggled with the tensions in reconciling these worlds that are intuitively linked but, at times, feel to be worlds apart in practice. As part of a graduate qualitative research course, I had opportunity to explore those tensions by delving into the literature and speaking with a practicing oncology nurse about her lived experience. A review of the literature (described in greater detail in Chapter 2) revealed that although there is growing literature about the shifting context of oncology and palliative care, little is known about the experience of oncology nurses who work in outpatient care settings providing non-curative treatment to patients and families living with advanced cancer. Although there were some writings about how palliative

care is thought of by oncology nurses, and some literature describing the experience of providing home care to people receiving non-curative chemotherapy, most studies were conducted outside of Canada and none had described providing this kind of care in an ambulatory cancer setting. Further, the discussion that I had with an oncology nurse as part of my coursework suggested that the experience of providing non-curative treatment in an ambulatory cancer setting is far more complex than what I had found described. This led to the question: How do oncology nurses working in an outpatient cancer setting experience providing non-curative care? How are cancer care and palliative care understood and enacted in practice? What tensions do oncology nurses experience within their daily work and how do they navigate them in their efforts to provide comprehensive cancer care?

Phenomenological Approach to Inquiry

A phenomenological research approach was used to gain a better understanding of oncology nurses' experience providing non-curative care in the community. This approach is based on the understanding that there are many realities in how we experience life and make meaning of those experiences. As a result, the experience of a particular phenomenon is complicated, and influenced by the many competing overlapping and often hidden assumptions that frame the way we see the world. The value of phenomenological research is that it has the power to make us "suddenly 'see' something in a manner that enriches our understanding of everyday life experiences" (van Manen, 1997, p. 345). With these new understandings our assumptions are challenged and there exists a possibility for becoming more human – more in tune with and sensitive to the complexity of the lived world, more compassionate, more accepting of difference.

From a nursing perspective, knowledge gained from diverse phenomenological perspectives can enhance our care and way of being both personally and professionally. The goal of this research is not to make generalizations about nursing experience but rather to highlight the complexities that are inherent in daily practice in a way that encourages discussion and new understandings.

Methodology

Oncology nurses who coordinate care or administer treatment to patients and families receiving non-curative cancer treatments were invited to participate in this study. Nurses were recruited from one of the six ambulatory cancer treatment facilities within an urban health region in western Canada. Ethical approval for this research was granted by the University of Victoria Human Research Ethics Committee and the University of Manitoba Education / Nursing Research Ethics Board. Permission to conduct research was granted by the research impact committees at each of the sites and written consent was obtained with each participant.

Nursing leadership of each site assisted with advertising the study either via staff email or by circulating study information within the clinic / treatment area. A total of eight oncology nurses from diverse settings volunteered to participate in a 60 to 90 minute interview where they were invited to talk about personal experiences providing non-curative care to patients and families living with advanced cancer. Non-curative therapy was understood to be any treatment that is given with the hope of controlling the disease or its symptoms while recognizing that the disease would not be cured with this treatment (i.e. palliative intent chemotherapy, palliative intent radiation, and supportive therapies such as intravenous hydration, blood transfusions, antibiotic therapy, etc.).

Interviews were audio recorded and personally transcribed for analysis, participants completed a demographic questionnaire following our conversation to provide information about the context of their work experience, and I kept a reflexive journal to document decisions throughout the research and reflect upon my own assumptions and evolving understandings as I engaged in the material that was shared. An in depth description of the philosophical underpinnings of the phenomenological approach and methodology used in this inquiry can be found in Chapter 3.

Interpretation

In keeping with the philosophical underpinnings of phenomenology, the process of interpretation or ‘coming to an understanding’ evolved as a back and forth immersion in the audio recordings of conversations with participants and transcribed records while consciously reflecting on (and questioning) what I was hearing and what this might mean. Each conversation was interpreted as its own understanding – a snapshot in time of the thoughts, feelings, perceptions, struggles and rewards the oncology nurse experiences in her daily work while caring for people with advanced cancer who are receiving non-curative treatment in the outpatient ambulatory care setting. As each understanding took shape, a larger picture of how oncology nurses experience providing non-curative care began to emerge. Emerging understandings were organized using the salient themes and sub themes that arose from the data.

Major themes arising from this work (described in greater detail within Chapter 4) include:

1. 'Safe Harbour and Defensive Nursing': A discussion of how oncology nurses think and feel about the role they have providing comprehensive cancer care to patients and families living with advanced cancer.
2. 'Balancing Hope and Miracles with Honesty and Witnessed Suffering': An exploration of competing internal and external tensions oncology nurses experience when providing non-curative treatment and care to patients and families living with advanced cancer.
3. 'The Safety Net': A discussion about oncology nurses' experiences in 'working the system' to reduce patient and family vulnerability while receiving non-curative treatment.
4. Staying in touch and letting go: A discussion about how oncology nurses experience the sharing or transition of care and cumulative loss.

Understandings gained through this study suggest that oncology nurses' experience of providing non-curative treatment within an outpatient cancer setting is extremely complex and multifaceted. Within this experience, oncology nurses balance two simultaneous objectives that can sometimes be in odds with one another in their vigilance to attend to both the emotional and physical safety of patients receiving non-curative treatment. On the one hand, the oncology nurse seeks to preserve and respect their patient's hope for prolonged survival with continued non-curative treatment, and on the other, oncology nurses struggle to 'keep it real' by revisiting treatment decisions in the context of witnessed suffering and trying to construct a 'back up plan' to rescue patients should they run into crisis in the community. Within each of these objectives lie inherent overlapping tensions that are shaped by the various conceptualizations of how both

cancer care and palliative care are understood, how treatment decisions are framed within their care team, and organizational constraints in the provision of services in the community.

Discussion

This study reveals the many intriguing and at times conflicting tensions inherent in oncology nurses work as they provide non-curative treatment to patients and families living with advanced cancer in the outpatient cancer setting. A discussion exploring how these new understandings relate, challenge or add to previous understandings about how non-curative cancer care is experienced is found in Chapter 5. Topics raised for discussion include:

1. Palliative care in oncology nursing practice: A discussion about how palliative care is understood and enacted in daily oncology nursing practice.
2. Goals of Care Discussions: A discussion about the oncology nurses role in goals of care discussions and other understandings that may contribute to how this role might be understood.
3. Anticipating Crisis: A discussion about the phenomenon of witnessed suffering and exploration of the possibilities in building a 'durable safety net'.
4. Cumulative loss and the emotional burden of witnessed suffering: An exploration of the oncology nurse-patient relationship and finding sustenance through loss.

New and re-visited understandings about: the primacy of the oncology nurse - patient relationship and natural tensions inherent in establishing professional intimacy and bearing witness to suffering and loss, the overarching desire to provide holistic care that is attuned to the physical and emotional vulnerability of patients and families living

with advanced cancer and organizational structures that inhibit these efforts, the dynamic of bearing witness to hope and suffering while ‘testing the water’ to introduce the comfort care alternative while maintaining a neutral stance so as not to bias decision making, and the moral distress experienced when ‘patchwork’ services fail to protect the patient who is receiving non-curative treatment from crisis all provide opportunities for further discussion about how these understandings may inform practice. These understandings (discussed in greater detail within the final chapter of this work) add to what is previously known about this phenomenon and provide new opportunity for supporting oncology nurses in the provision of non-curative care to patients and families living with advanced cancer.

Chapter 2

Review of the Literature

As discussed previously, notions of what constitutes quality oncology care and what constitutes quality palliative care are in a state of evolution. Advances in non-curative cancer treatment and supportive therapies, tensions between shifting values of what “ought to be” and “what is” included as part of comprehensive care, historic tensions between the ‘cure-driven’ model of oncology care and the ‘comfort care only’ palliative model, and the simultaneous, yet separate, evolution of cancer care and palliative care as distinct specialties and services are but some of the contextual realities described in the literature that add to the complexity of providing comprehensive cancer care. The following review will explore these understandings and how services are currently provided. Current understandings of how these tensions are experienced and navigated by oncology nurses will be explored highlighting the gaps in what is known and the relevance of this study.

Palliative Care: Shifting Paradigms

The revolutionary work of Dame Cicely Saunders in the 1950’s and 1960’s paved the way for modern palliative care philosophy with the recognition that both medical innovations in pain and symptom management and concern for the emotional and spiritual needs of patients and their families were required in the care of the dying (Ditillo, 2002). Palliative care services developed in the mid-1970’s and early 1980’s were designed to provide multidisciplinary care for the dying using these principles, and to this day, largely service those with advanced cancer in the final months of life (Gaudette, et al., 2002).

Early definitions of palliative care were consistent with this approach. The World Organization first defined palliative care in 1986 as:

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with anti-cancer treatment (World Health Organization, 1990).

While this definition was instrumental in raising the awareness of palliative care as ‘active care’, it came to be regarded as limited or ambiguous through the interpretation of what is meant by ‘responsiveness to curative treatment’ (Ahmedzai, et al., 2004). The most recent WHO definition is more explicit and inclusive when defining a population that would benefit from a palliative approach to care.

Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual... applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (World Health Organization, 2010, para. 1).

This definition is congruent with current research supporting the integration of

palliative care earlier in the disease trajectory. As mentioned previously, palliative care has been associated with positive outcomes in both the patient and families experience including: enhanced patient care (Higginson, et al., 2002; Higginson, et al., 2003), patient satisfaction (Rabow, Schanche, Petersen, Dibble, & McPhee, 2003), family caregiver satisfaction (Gelfman, Meier, & Morrison, 2008; Hearn & Higginson, 1998), help with understanding the diagnosis and prognosis (Ellershaw, Peat & Boys, 1995; Jack, Hillier, Williams, & Oldham, 2004), and improved symptom management (Hanks, et al., 2002; Thomas, Wilson & Sheps, 2006). Conversely, increased symptom distress is strongly associated with psychological distress, reduced quality of life scores and shortened survival (Griffin, Koch, Nelson, & Cooley, 2007).

While integrated oncology and palliative care services are widely recognized as valuable for those living with advanced cancer, there is less clarity about how these services are best provided. Various conceptual models for palliative care delivery in tandem with anti-cancer therapy have been proposed. The World Health Organization (1990) proposed a continuum of palliative care within the overall management of patients with progressive cancer. Using this 'Integrated Model of Care' model, as a person's disease advances and there is less to offer in terms of treatment to slow disease progression or prolong life, the focus of care should progressively shift toward comfort care and quality of life (See Figure 1).

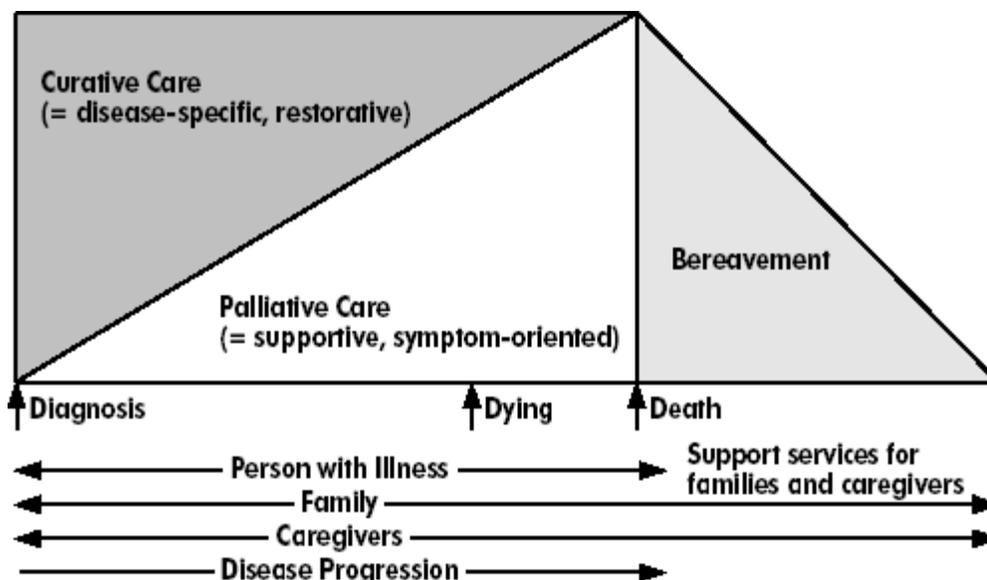


Figure 1: Integrated Model of Care (World Health Organization, 1990)¹

In an expanded conceptualization of the integrated model described above, Milstein (2005) proposes a universal integrative paradigm of care that introduces concept of healing in place of ‘palliation’. She proposes that the process of healing (and palliation, or end of life care, when indicated) ought to occur in tandem with disease focused treatment and begin at the time of diagnosis of serious illness. This model also expands upon past models in recognizing loss and bereavement as a continual process throughout the course of illness and noting that the approach taken by health care providers in providing care should be more of the mindset of ‘being with’ rather than ‘doing to’. (See Figure 2).

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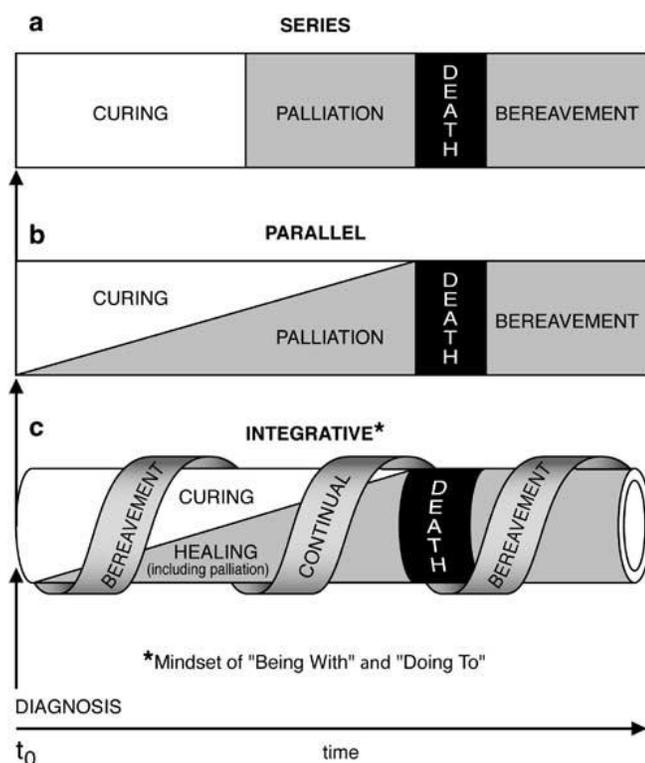


Figure 2: (c) Universal Integrative Paradigm of Care (Milstein, 2005, p. 564)²

The European School of Oncology proposes an alternative model of service delivery that integrates three levels of palliative care within oncology care: basic palliative care (person centered attention to physical symptoms and the psychological, social, existential and cultural needs of those diagnosed with a life limiting illness as a core competency of all health care providers), specialized palliative care (providers trained at an expert level working as part of a multi-disciplinary team to provide consultative support with complex problems and to build capacity of basic palliative care provision through education and mentorship), and end-of-life care (a collection of services with specialty team members who provide care in the final days and weeks of life) (Ahmedzai, et al., 2004).

² Reprinted with permission from Macmillan Publishers Ltd: JOURNAL OF PERINATOLOGY. Milstein, J. A paradigm of integrative care: Healing with curing throughout life, "being with" and "doing to", 25, 563-568, copyright (2005).

This integrated approach has been described in some American studies as ‘simultaneous care’. Using this model, patients are not asked to choose between two options that may each offer benefit. Palliative care is offered in tandem with disease focused therapy throughout the trajectory of illness. In other words, care is provided using a philosophy of patient and family centered care with attention to the physical, emotional, spiritual and practical implications of living with advanced cancer while the patient receives treatment to slow the progression of disease or alleviate symptoms (Meyers, Linder, Beckett, Christensen, Blais, & Gandara, 2004, p. 555). The simultaneous model goes beyond a holistic approach to care to include access to palliative care specialists through consultation and admission to acute palliative care units when required (Hui et al., 2010), and access to hospice benefits while the patient receives disease focused treatment or participates in clinical investigational trials (Meyers, Linder, Beckett, Christensen, Blais, & Gandara, 2004). Most U.S. hospice programs do not offer this option as the Medicare Hospice Benefit that pays for 80% of hospice care does not cover the cost of clinical trials or expensive disease focused therapies (Meyers & Linder, 2003, p. 1413). However, studies evaluating the impact of simultaneous care models suggest many benefits including increased rates of hospice enrolment and earlier hospice utilization (Meyers & Linder, 2003; Meyers et al., 2004; Ford Pitorak, Beckham Armour, & Sivec, 2003), decreased emergency room usage and hospitalization (Beresford, Byock, & Sheils Towhig, 2002), and improved quality of life (Esper, et al., 1999; Ford Pitorak, Beckham Armour, & Sivec, 2003).

Along a similar vein, Gillick (2005) argues that defining palliative care as ‘complementary’ to life prolonging therapy rather than as a central paradigm for caring

for persons with progressive, life-threatening illness, perpetuates the false dichotomy between curative and palliative care. She argues that because the treatment of persons with serious and complex illnesses is seldom curative, it makes more sense to think of the approach as inherently palliative. As such, all therapies should be considered while weighing the likelihood of success, potential toxicities of treatment in the context of the person's goals of care. An interdisciplinary approach that attends to advance care planning, managing symptoms and the embodied experience of living with illness should be a standard of care for all.

“Palliative”: What's in a name?

Although there is growing evidence to support the integration of palliative care within comprehensive cancer care, the evolving conceptualization of what constitutes palliative care and lack of clarity about its meaning is cited by some to be problematic in blurring the transition points that patients and families experience (Larkin, Diercix de Casterle & Schotsmans, 2007; Van Kleffens, Van Baarsen, Hoekman, & Van Leeuwen, 2004). Research exploring factors that contribute to the underutilization of hospice or palliative care services frequently cite misconceptions about what palliative care is or what it can provide as a barrier to accessing service (Lofmark, Nilstun, & Agren Bolmsjo, 2007; Ahmed et al., 2004a). There is often a general lack of understanding amongst professionals about whom to refer and when, challenges in predicting prognosis (Ahmed et al., 2004a; Bestall et al., 2004), equating of palliative care with ‘pulling the plug’ and belief that it is an option only when ‘nothing more can be done’ (Weinstein, 2001), and concerns of diminishing a patient's sense of hope (Rodriguez, Bernato, & Arnold, 2007). Patients and families are frequently reported to be reluctant to be referred

to palliative care because of misunderstandings of what it is offered, a perception that they will be denied some elements of care, or fear of its association with imminent dying (Ahmed et al., 2004a).

Research suggests that the use of the word ‘palliative’ may feel uncomfortable to health care providers in the oncology care setting. A recent study conducted by Fadul et al, (2009) suggests that oncologists would be more likely to refer patients to ‘supportive care’ services than ‘palliative care’ services due to the perception that the term ‘palliative care’ may increase patient feelings of distress and reduce hope. This finding is perhaps not surprising as the term ‘supportive care’ is frequently used within the cancer literature to describe the ‘palliative’ or perhaps ‘holistic’ approach used by the oncology care team to managing the symptoms of cancer and its treatment such as chemotherapy induced nausea and vomiting, pain, treatment related cytopenias, and the psychosocial aspects of coping with a cancer diagnosis (Esper, Hampton, Finn, Smith, Regiani & Pienta, 1999; Finlay & Casarett, 2009; Turner, Clavarino, Yates, Hargraves, Connors, & Hausmann, 2007).

It seems that these multiple understandings about the meaning of palliative care and when it ought to be introduced in a patient’s care prevail because the term is used to describe both a philosophy of care and a collection of services that are provided to patients and families at end of life. As a philosophy of care, the meaning of ‘palliative care’ as defined by the World Health Organization seems closely related to concepts of ‘holistic’ or ‘patient and family centered care’ described in nursing literature and concepts of ‘supportive care’ in oncology literature. The Canadian Nursing Association Code of Ethics for Registered Nurses (2008) recognizes comprehensive care as a core

value and responsibility of nurses in all practice settings stating “In all practice settings, nurses work to relieve pain and suffering including appropriate and effective symptom management, to allow persons to live with dignity” (p. 14). Further, nursing theoretical frameworks within the human science paradigm such as those proposed by Newman, Paterson and Zderad, and Parse are grounded in philosophy that values the provision of holistic care through relationship in a manner that respects the patient and family’s goals of care (Hartrick Doane, & Varcoe, 2005, chapter 3).

Given the emphasis of holistic care in general nursing practice, and the many articles describing supportive care for patients and families living with cancer, it would seem that from a philosophical standpoint, ‘palliative care’ could be considered a core component of cancer care and of nursing care in general. However, some studies suggest that the implementation of this philosophy in nursing practice within the oncology setting can be difficult. Willard and Luker (2005) conducted a qualitative study exploring how nurses who were employed within hospital based cancer settings to provide ‘supportive care’ experienced the enactment of their role in practice. They found that the dominant focus on investigating, diagnosing and treating cancer within the cancer setting created the largest challenge to oncology nurses providing supportive care. Further, authors note that “it was apparent that the treatment agenda shaped the organization of services - particularly the type of support offered, determined professional boundaries and relegated support to a subordinate position in patient care” (Willard & Luker, 2005, p. 329). This study suggests that the enactment of ‘supportive care’ or ‘palliative care’ philosophies in oncology nursing practice is complex arguing for a need to explore the tensions inherent in daily practice. Further, it is unknown how oncology nurses may experience providing

supportive or palliative care within the ambulatory cancer care setting or in the Canadian context.

Palliative care as a collection of end-of-life services

The lack of congruity between services that “ought to be” delivered within the expanded conceptualization of palliative care and services that exist is also cited as problematic in perpetuating the dichotomy between curative and palliative care (Byock, 2000; Carlson, Morrison, & Bradley, 2008). Current funding models and service provision criteria necessitate an ‘either / or’ approach to treatment rather than the ‘both / and’ treatment option idealized in current palliative care philosophy (Byock, 2000; Carlson, Morrison & Bradley, 2008; Carstairs, 2010). Further, in many parts of Canada, eligibility to receive coordinated palliative care services is based on an arbitrary time limit or prognosis that restricts access to services and benefits to the last few months of life (Carstairs, 2010). To quote Senator Carstairs:

This approach puts doctors between the proverbial rock and hard place. They are put in the role of gatekeeper, yet they can only allow access to services if they predict that someone will die within a very specific, and very short, amount of time. Such a predicament is fraught with ethical, medical and scientific problems. It is no wonder they are reluctant to make it, yet this reluctance effectively denies services to untold numbers of patients in need. (2010, p. 23)

It is widely recognized that the cost associated with providing care to those receiving disease oriented treatment would necessitate re-evaluation of funding models (Carlson et al., 2008; Carstairs, 2010; Smith, 2003; Matsuyama, Reddy & Smith, 2006). However the culture of health care is often perceived to make care of the dying a low

priority when stretching limited resources. Participants in Senator Carstairs' recent study exploring the status of palliative care in Canada frequently expressed disappointment that palliative care is considered to be 'boutique' care, citing the common view shared by administrators, and even non-palliative care practitioners that resources devoted to dying patients are 'wasted' (2010, p. 13).

One could argue that this devaluing of palliative care is reflected in the way that services are funded in many parts of Canada. Only four provinces have designated palliative care as a core service of the provincial health care program with a separate budget line. Other provinces offer palliative care services but as a sub section of other services and palliative care continues to be largely funded by charitable donations (Carstairs, 2010, p. 43).

Further, it could be argued that in times of fiscal constraints, palliative care initiatives are easily sacrificed. In 2005, the federal government invested \$16.5 million through the Canadian Institute of Health Research to fund collaborative research in palliative care. With this funding, research partnerships from across the country were established and Canada was well on the way to becoming a leader in palliative care research to inform public policy and clinical practice. Despite the success of this initiative, grant funding expired in 2009. In the current climate of global economic restraint, there are no plans to invest new funds for new research or to translate past research into practice (Carstairs, 2010).

So although there is a philosophical evolution to conceptualize palliative care as an integral part of comprehensive care, it would seem that the socio-political context of current health care services have yet to 'catch up' to this vision. In many parts of Canada, the provision of coordinated palliative care services necessitates an 'either/or'

decision. Patients, families and their oncology care providers are challenged to choose between non-curative intent treatment and access to coordinated palliative care services. Little is known how oncology nurses experience providing care to those with advanced cancer in this 'either / or' context.

Cancer Care: Shifting Paradigms

The last 50 years have seen significant advances in cancer screening, diagnosis and treatment (American Cancer Society, 2009). There has been a rapid growth in the types of treatment used to treat cancer including; the use of hormone therapies, the advances in radiological treatment (for example, use of gamma knife), the use of combination chemotherapy to improve response, advances in immunotherapy (with agents such as Rituxan®), and the development of targeted therapies (for example Gleevec®, Irressa®, and Herceptin®) to name but a few. (American Cancer Society, 2009; Canadian Cancer Society, 2009b).

At the forefront of this research is the goal of prolonging survival with the hopes of ultimately curing disease. However, although treatments may be 'curative' for some, in others treatment does not cure but rather stabilizes the disease or slows progression allowing people to live longer with their illness. As a result, cancer is increasingly regarded as a chronic disease (Smith, 2003). The expanded toxicity profile of existing and newer agents, the cumulative symptom burden associated with both the disease and its treatment, and the fact that people are living with cancer over a longer period are factors that suggest a need for integrated palliative management of symptoms throughout the illness trajectory (Ferrell, Paice & Koczywas, 2008). However, little is known about how oncology nurses working in an ambulatory care setting experience providing non-

curative care to patients and families living with the growing symptom burden of advanced cancer and its treatment.

‘Curative’ vs. ‘Palliative’ Treatment

In the context of advanced metastatic diseases, cancer treatment is often offered as a means to prolong life and reduce symptoms associated with tumour burden (Craft, Burns, Smith & Broom, 2005). Current research supports the use of ‘non-curative’ or ‘palliative’ chemotherapy to slow the progression of several cancer illnesses (McCall & Johnston, 2007). A recent review of the use of chemotherapy in addition to supportive care in advanced or metastatic gastrointestinal cancer reported improvement in survival and quality of life and delays in disease progression in comparison to supportive care alone (Ahmed, Ahmedzai, Vora, Hillam, & Paz, 2004b). Studies have also reported survival benefits for diseases such as non-small cell lung cancer (Numico, Russi, & Merlano, 2001), advanced breast cancer (Archer, Billingham, & Cullen, 1999; Fallowfield, 2004), and improvements in tumour related symptoms (Archer et al, 1999).

The addition of ‘non-curative’ disease focused treatment in the management of advanced illness has further ‘blurred the lines’ between what was once understood as the division between curative and palliative care. Although oncologists may discuss treatment intent when discussing options with patients and their families, research suggests that patients and families frequently misinterpret the intent of treatment and assume treatment is intended to cure the disease (Craft, Burns, Smith, & Broom, 2005; Van Keffens, Van Baarsen, Hoekman, & Van Leeuwen., 2004). Craft et al. (2005) reported that less than half of the participants in their study correctly understood the intent the non-curative treatment they were receiving. Almost one third believed their

treatment was curative and 20% indicated that they did not know the intent of treatment. Interestingly, for some of the participants, perceptions of the intent of treatment changed over the course of time. Of the 40 patients who initially believed their treatment to be curative, only 24 repeated this response 12 weeks later. Conversely, 5 participants who had initially understood their treatment to be non-curative changed their response at week 12 to understanding treatment to be curative. However, on the whole, participants tended to clarify their understanding of treatment goals over the duration of their illness.

There are several factors reported in the literature that are suggested to contribute to the misunderstanding of treatment intent in advanced illness. First, medications typically used with curative intent in earlier stages of the disease are also often used with non-curative intention in those with advanced illness (Van Kleffens et al., 2004). Secondly, patients receiving non curative treatment can misinterpret the meaning of anti-tumour response and be inclined to see this as a signal towards potential cure. In such cases, 'success' is transient because of acquired resistance and treatment eventually loses effect (Van Kleffens et al., 2004). Little is known about how oncology nurses who administer non-curative intent treatment may experience a patient's shifting understanding of treatment intent or how they negotiate this as part of a larger team.

Oncologist participants in the Van Kleffens et al. (2004) study noted that the distinction between whether a treatment is palliative or curative is important for three reasons. First, being clear about the intent of treatment gives patients and their families an indication of the severity of their illness and limited prognosis. Secondly, the intent of treatment influences what level of toxicity may be acceptable for the doctor and patient. And finally, the intent of treatment was perceived to be a factor in how forcefully

oncologists would recommend treatment. Oncologists interviewed indicated that they would be inclined to exert more pressure to accept curative cancer treatment in someone with limited stage disease than they would with a non-curative goal. The ‘blurred lines’ between curative and palliative treatment add to the complexity of decision making and advance care planning (Van Kleffens et al., 2004). Little is known about how this ‘grey zone’ is experienced by nurses or the complexity of navigating these challenges with the families they care for.

Cure: What’s in a name?

Given the above, the notion of ‘cure’ bears as much attention as the notion of ‘palliative care’. It is common for cancer research fundraising and advocacy campaigns to be ‘cure focused’ and for the treatment or prevention of cancer to be framed in ‘battle language’ (Reisfield & Wilson, 2004). One typically does not have to look far to read about the “fight against cancer”. Fundraising slogans such as “Let’s make cancer history” and “Cancer can be beaten” frame living with cancer as a war to be won. Given the pervasive emphasis of cure when discussing health and illness in western society, it is perhaps not surprising that there is a widely held public perception that treatment will ultimately cure disease. A recent study conducted by Fishman, Ten Have & Casarett (2010) reviewed 436 articles printed in newspapers and national magazines in the United States and found that majority of studies discuss aggressive treatment and survival but rarely discuss treatment failure, adverse events or end of life. Authors in this study suggest that this portrayal of cancer care in the news media may give patients and their families an unrealistically optimistic view of cancer treatment, outcomes and prognosis.

These notions of ‘cure’ can be problematic in oncology practice. From a patient

or family perspective 'cure' may mean eradication of the disease with it never to return. However, the definition of 'cure' from an oncology perspective is less straightforward (Barnes, 2005). Objective definition of cure is limited by the inability to detect minimal residual disease with current testing methods. From an oncology perspective, the operational definition of 'cure' was developed by observing relapse rates over time. Five year survival is often the time quoted for 'cure' but relapse rates within this time period are variable depending on the disease, and relapse, although less common, remains a possibility after this time (Barnes, 2005).

Gaps in Knowledge

Although there have been several recent studies exploring the experiences of nurses providing care to those with advanced cancer, there is little written about how oncology nurses working in an outpatient setting experience providing non-curative intent cancer treatment and support in the Canadian context. Dunne, Sullivan & Kernohan (2005) explored district (home care) nurses' experiences providing palliative care for people with cancer in the UK and Andrew & Whyte (2004) explored district (home care) nurses' experiences providing care to people receiving palliative chemotherapy. In each of these studies, participants were home care nurses providing palliative care to oncology patients in contrast to this study.

In an Irish study, Mcilpatrick, Sullivan & McKenna (2006) asked oncology nurses to compare their experience of administering chemotherapy on an inpatient unit with how this is experienced in the outpatient setting. This study highlighted some of the tensions that nurses experienced balancing task focused care with the holistic care they aspired to provide, however the provision of non-curative treatment was not a focus of this research.

There has been some recent research exploring oncology nurses' perceptions and understandings about the meaning of palliative care and when it ought to be offered to patients and families. Bertero (2002) explored the meaning of palliative care with district (home care) nurses in Sweden, and Mahon & McAuley (2010) studied oncology nurses' personal understandings about the meaning of palliative care in the U.S.A. While these studies provide insight into how home care nurses (Bertero, 2002) and oncology nurses (Mahon & McAuley, 2010) understand palliative care, they do not explore the contextual complexity of how providing palliative care is experienced by oncology nurses in practice.

An Australian study explored oncology nurses' perceptions about the supportive care they provide to parents living with advanced cancer to identify the challenges and educational needs oncology nurses perceived in their practice (Turner, Clavarino, Yates, Hargraves, Connors & Hausmann, 2007). The focus of this study was to understand the challenges that oncology nurses experience providing care to patients who are living with advanced cancer and are parents to young children with a view of identifying the education needs of oncology nurses providing care. The study provides a rich description of the emotional toll of providing cancer care and feelings of uncertainty that oncology nurses experience while providing care to young families. However, it is uncertain how this might relate to oncology nurses' experiences providing non-curative care in the outpatient setting within the Canadian context.

Research exploring oncology nurses' attitudes towards death and caring for dying patients suggests that nurses with more knowledge of palliative care and clinical experience tend to be more comfortable caring for dying patients and have more positive

attitudes towards providing palliative care (Lange, Thom & Kline, 2008). However, once again, there is little research to illuminate how providing non-curative care is experienced by oncology nurses or the complexity of delivering care or coordinating services in an outpatient oncology clinic setting.

Several studies have explored oncology nurses experiences working in acute oncology inpatient units; in a study conducted in Manitoba, Hanson (1994) explored how the tacit knowledge of oncology nurses is drawn upon in daily practice to meet the psychosocial needs of patients, and in a UK study, Saltmarsh & Devries (2008) explored nurses experiences providing highly toxic chemotherapy in inpatient stem cell transplant units and the paradox of providing hope for cure while causing suffering. Van Rooyen, le Roux & Kotze (2008) explored the experiential world of the oncology nurse working in an inpatient unit of a private hospital in South Africa. While this study provides valuable insight into how oncology (and palliative care) is experienced by oncology nurses through relationship (with patients and families, the multidisciplinary team and with self), it may not reflect the experiences of oncology nurses working in the outpatient setting in the Canadian context.

Significance of the inquiry

The specialties of medical oncology and palliative care each add a valuable dimension in the care of patients and families living with advanced cancer. In keeping with the traditions and historical evolution of each specialty, nurses in oncology practice have developed sophisticated knowledge of treatments used to modify and control cancer illness while palliative care providers have developed expertise in the use of symptomatic treatments and having difficult discussions with patients and families in a time of

emotional, physical, and existential crisis. The shifting context of this care challenges health care providers to critically examine current practice to ensure patients and families receive the best of both worlds, at all points in the cancer trajectory, while acknowledging the distinct skills of the health care professionals who care for them.

Given our limited understanding of how the tensions inherent in the various conceptualizations of both cancer and palliative care are understood and experienced within outpatient cancer settings, a phenomenological approach to inquiry was used to help answer the primary research question: How do oncology nurses working in an outpatient care setting experience providing non-curative cancer treatment in their daily practice? Related to this, how are the various understandings of both advanced cancer care and palliative care that are described in the literature experienced in the lived practice of oncology nurses working in outpatient settings? How do these understandings unfold in the provision of advanced cancer care? How are discussions about goals of care and transition to palliative care services at end of life experienced by oncology nurses in the outpatient setting? And how do oncology nurses navigate the tensions inherent in their work? The following chapter will discuss the methods used in using a phenomenological approach to gain a better understanding of this experience.

Chapter 3

Approach to Inquiry

The underlying assumptions, beliefs and values that are held (worldview), and the socio-political context of that worldview, shape our understanding of the world and all that is within it (McIntyre & McDonald, 2010). Thinking critically about one's personal worldview and being explicit about underlying assumptions and beliefs is an important step in framing how one approaches a phenomena of interest of interest, what questions are asked, and how those questions are explored (Munhall, 2007a). A phenomenological approach was used in this study to explore the lived experience of oncology nurses providing non-curative care within the ambulatory cancer setting. As described by van Manen (1997) phenomenological text has the power to make us "suddenly 'see' something in a manner that enriches our understanding of everyday life experiences" (p. 345). It has the potential to take readers beyond the taken-for-granted aspects of life to challenge preconceptions and lead to a new way of seeing ourselves when we observe the world. With these new understandings our assumptions are challenged and there exists a possibility for becoming more human – more in tune with and sensitive to the complexity of the lived world, more compassionate, more accepting of difference. From a nursing perspective, knowledge gained from diverse phenomenological perspectives can enhance our care and way of being both personally and professionally. This research reveals previously unexplored understandings about how oncology nurses experience providing non-curative care to patients and families living with advanced cancer. With these understandings come new opportunities for supporting oncology nurses in their work and enhancing the care of patients and families living with advanced cancer.

This chapter explicitly describes the worldview and underlying assumptions that guide this work. It includes a brief review of how I came to be interested in this phenomenon, a description of my personal world view (or the ontological and epistemological assumptions guiding this pursuit of understanding), an overview of the tenets of phenomenological inquiry used to guide this study, and a detailed account of the steps taken throughout the course of this research.

Coming to the question

As described in chapter 2, traditional curative oncology and palliative care services, once conceptualized as polar opposites of the cancer illness continuum, are increasingly being conceptualized as partners in a more integrated, holistic, interdisciplinary approach to cancer care. Given the nature of the cancer experience – and the complex physical, emotional, spiritual, and practical implications of being diagnosed with advanced cancer, a blended approach that incorporates the knowledge and skills of both oncology and palliative care specialties is intuitively appropriate in ensuring that patients and families living with advanced cancer receive the treatment and support they require throughout the trajectory of their illness.

While this integrated model reflects the preferred vision of comprehensive cancer / palliative care, the provision of existing services does not often reflect this vision. Locally, and in many parts of Canada, eligibility for enrolment to receive coordinated palliative care services and benefits is limited to include those with an identified prognosis of less than six months who have decided to forgo further treatment with systemic chemotherapy. Although it is widely recognized that people living with advanced cancer would benefit from a combined palliative / oncology approach

throughout their illness, the majority receive palliative care through formal palliative care services late in the illness when attempts to cure or slow the progression of disease have failed.

As described in the previous chapter, notions of what constitutes oncology care and what constitutes palliative care are in a state of evolution. Advances in non-curative cancer treatment and supportive therapies, tensions between shifting values of what “ought to be” and “what is” included as part of comprehensive care, historic tensions between the ‘cure-driven’ model of oncology care and the ‘comfort care only’ palliative model, and the simultaneous, yet separate, evolution of cancer care and palliative care as distinct specialties and services are but some of the contextual realities described in the literature that add to the complexity of providing comprehensive cancer care. However very little is written about the experience of oncology nurses providing non-curative treatment within this context, and I was unable to find any literature describing how this might be experienced within an ambulatory cancer setting.

Throughout the course of my career I have practiced in ‘both worlds’, first as an oncology nurse working in both the acute inpatient and outpatient care settings and later in my current role as a clinical nurse specialist within the urban regional palliative care program. I have personally struggled with the tensions in reconciling these worlds that are intuitively linked but, at times, feel to be worlds apart in practice. As part of a graduate qualitative research course, I had opportunity to explore those tensions by delving into the literature and speaking with a practicing oncology nurse about her lived experience. Our discussion suggested that the experience of providing non-curative treatment in an ambulatory cancer setting is far more complex than what I had found

described in the literature. This lead to question: How to oncology nurses working in an outpatient cancer setting experience providing non-curative care? How are cancer care and palliative care understood and enacted in practice? What tensions to oncology nurses experience within their daily work and how do they navigate them in their efforts to provide comprehensive cancer care? As will be discussed, both my personal worldview and the tenets of the phenomenological approach to inquiry fit with the objectives of this inquiry.

Positioning of Self in the Research Process

Ontology

My worldview is consistent with the traditions of interpretive inquiry. My understanding of the nature of reality (ontology) are similar to that of Benoliel (1984), namely that;

- human beings are active agents that construct their own realities,
- social life is the shared creativity of individuals and their perceptions,
- the character of the social world is dynamic and changing,
- there are multiple realities and frameworks for viewing the world: the world is not independent of humankind and objectively identifiable

(Cited in Munhall, 2007b, p. 86-87)

In other words, the nature of our lived reality is complex and changing, and our interpretation of lived experience is co-created as a part of the larger world.

Epistemology

Building on the above assumptions, I understand human beings to be complex,

holistic beings. As such, it is impossible to achieve a complete understanding of the whole by evaluating parts. That is not to discount the valuable contribution that research derived through post-positivist traditions has made in health research. However, I believe the complex nature of what it is to be human precludes generalizations. My leaning toward interpretive inquiry is, as Munhall (2007b) describes, “not a negation of science, but a recognition of a ‘more’” (p. 87). In other words, there exists no “one truth”, but rather multiple realities for viewing the world. Exploring those multiple realities is critical to learning about the ‘more’.

Informed by this understanding of multiple realities, knowledge is subjective and there are no absolutes in predicting outcomes. Rather, through an interpretive worldview, knowledge is an exercise of mutual interpretation and is derived from meanings within the context of lived experience (Munhall, 2007a). The researcher seeks to explore how the self is socially constructed, how a person narrates their own story, and how truth is an interpretation of both the participant and researcher.

The Phenomenological Approach

The philosophical tenets described above are consistent with the historical constructs of western phenomenological perspectives that form the foundation for modern phenomenological approaches to inquiry. Merleau-Ponty (1962) theorizes that we make meaning of our experience through consciousness or the sensory awareness of and response to the environment (i.e. the unity of the mind and body in navigating the context of the lived world) (as cited by Munhall, 2007c). Experience and perception are our main forms of consciousness and are shaped by our embodiment (bodily way of being through which we gain access to the world) and our natural attitude (the largely

unexamined past experiences, values, beliefs, and traditions that frame our assumptions through which the phenomenon is interpreted) (Munhall, 2007c). Simply stated, the experience and interpretation of a phenomenon is unique to the individual and is constructed through complex interactions between one's engagement as a holistic being in the lived world and the context of that lived world. Heidegger (1927/1962) builds upon this understanding of 'natural attitude' by acknowledging the cultural, social, and historical context that shape both how a phenomenon is experienced and the meaning given to that experience (Munhall, 2007c). Inherent in this approach is attention to language - both to what is said, and what is not said - to go beyond the mere description of the experience to include a thoughtful analysis of the meaning of the experience and how these meanings are constructed. Seen in this light, phenomenology is more than simply identifying and explaining current and shared meanings. Rather, it seeks to critique these meanings and illuminate opportunities to enhance nursing practice.

Ultimately, the goal when using this approach is to gain a deeper understanding of an individual's perspective and to present it in such a way that resonates with our understanding of what it means to be in the world. The text should illuminate the irrevocable tensions that are inherent in the lived experience and illustrate not only what the text says, but how it speaks to inspire understanding (van Manen, 1997). The resulting phenomenological text is not intended to be 'generalizable' in the positivist sense, but rather to evoke new understandings in illustrating the rich complexity of individual interpretations.

This approach requires that the researcher assume a reflective stance of unknowing. Nothing is assumed or taken for granted. Phenomenological inquiry invites

the questioning or challenging of taken for granted assumptions to increase our understanding of a phenomenon (Bergum, 1989). The researcher is conceptualized as an instrument of inquiry and is called to set aside ‘what you think you know’ about the phenomenon to discover what is truly being said in the conversation (Bergum, 1989). As depicted by Kvale (1996) the researcher is viewed as traveler on a road to discovery for which there is no map. Munhall (2007c) asserts that the inherent need for flexibility to ‘go where the material takes you’ precludes the development of any one particular method in conducting phenomenological research. Rather, the steps taken by the researcher must come from and stay true to the philosophical underpinnings of phenomenological inquiry.

Process of Inquiry

Context

Oncology nurses who were employed through the primary provincial cancer treatment center (two sites) or one of the four community oncology clinics within an urban health region in central Canada were invited to participate in this study. Within the urban health care region, access to formal or case coordinated palliative care services is available if the patient is expected to have a prognosis of less than six months and if their goals or expectations of care are consistent with treatment offered through the palliative care program (i.e. there has been a decision to stop chemotherapy and forgo attempts at cardiopulmonary resuscitation). Benefits to enrolment in coordinated palliative care services include: palliative care based case coordination, palliative home care nursing, and admission to hospice residence if eligible, the possibility of direct admission to a palliative care inpatient unit in times of crisis if a bed is available, and enrolment in the

provincial palliative care drug access program. Patients receiving non-curative chemotherapy who do not qualify for coordinated palliative care services receive care coordinated through the oncology clinic and have access to home care services (where a palliative community nurse can be requested), referral to oncology based pain and symptom management clinics for complex symptom needs, referral to psychosocial oncology counsellors and oncology based supports (“Kids can cope” and other support groups, “Look good, feel better” program, etc.), and consultation with palliative care specialists as needed. Oncology nurses who coordinate or administer outpatient non-curative intent treatment within this context were invited to participate in this study.

Recruitment

Following ethical approval and permission to conduct research in each of the research sites (see Appendix A for letter requesting permission to conduct research), an invitation to participate in this study (see Appendix B) and a synopsis describing the intent of the study, focus of inquiry, and contact information of the primary investigator (see Appendix C) was circulated via email with the help of nursing leadership. One follow-up email inviting oncology nurses to participate was sent two months into the study to complete recruitment. In sites where nurses did not have email access, paper copies of the invitation to participate (Appendix B) and study synopsis (Appendix C) were distributed by patient care managers for circulation to oncology nurses.

Ethical Considerations

Ethical approval for this study was obtained through the University of Victoria Human Research Ethics Board in accordance with the Tri-Council Policy Statement on

the Ethical Conduct for Research Involving Humans. Ethical approval was also obtained through the University of Manitoba Research Ethics Board as this study was conducted in the province of Manitoba. Permission for site access was obtained through each facility's respective research impact committee.

Oncology nurses were invited to participate in 60 – 90 minute, face to face, audio-taped interview at a time and location, outside of normal working hours, that was convenient to the participant. Two copies of the consent form designed for the purposes of this study were provided to each participant (see Appendix D). Following joint review of the consent and answering any questions participants may have had about the study, the principle investigator retained a signed copy for study records and provided the participant with a copy. All study information including completed consent, audio-recordings and transcripts are kept in a secured location with restricted access. All information that has the potential to reveal a participants identity was removed from the transcripts. Material will be destroyed three years following the completion of this study.

The tenets of phenomenological inquiry have further ethical implications that go beyond 'confidentiality' and 'anonymity' when thinking about the ethical obligations of the researcher. These ethical obligations also extend to include how research is conducted and what is ultimately 'given back' as a result of the research. Using interpretive inquiry, the researcher assumes an open and unknowing stance, recognizing the participant as the expert of their experience. The process involves an authentic respect for differences, authentic caring about how the person perceives the world and an overarching commitment to faithfully represent the participant's experience (Munhall, 2007a). The next level of responsibility involves the 'giving back' the research in a meaningful

way that informs practice. Using interpretive inquiry, a researcher has the opportunity to “reveal what has been concealed” (Munhall, 2007a, p. 11), legitimize the experience of others in their difference, and describe a new way of looking at the world. These understandings guided my approach throughout the research process. The findings of this research will be shared with oncology nurses in each site via presentations upon completion.

Participants

A purposeful sampling of oncology nurses who work in outpatient oncology clinics and treatment areas was undertaken as part of this study. Purposeful sampling involves a deliberate selection of participants who may be considered experts in the phenomenon being explored. That is to say that participants who have lived through or are presently undergoing the experience and are willing to talk, to reflect, and to share this experience with the investigator are deliberately selected to participate in the research (Morse, 2007). I have a particular interest in learning about how the social constructs of advanced cancer and palliative care are experienced in lived oncology nursing practice and the subtle tensions inherent in oncology nurses’ work while providing non-curative treatment that may not be readily understood by those outside this community. In the pursuit of greater understanding I purposefully invited oncology nurses working in diverse roles within ambulatory cancer treatment settings to participate in research conversations about their practice. The intent was to illuminate unique or diverse variations that have emerged in adapting to different care settings while providing insight into the essence of what it is like to care for families living with advanced cancer. As a result, oncology nurses who coordinate care for patients living with advanced cancer

(known locally as ‘clinic nurses’) and oncology nurses who deliver treatment (commonly referred to as ‘treatment room nurses’) working in ambulatory cancer treatment centers within the urban health region were invited to participate in this study.

Immersion

Munhall (2007c) describes ‘immersion’ as a critical process through which the researcher reflects upon their personal worldview and becomes well versed in phenomenological theory to ‘become phenomenological’. I have been immersed in this subject for years within my own work, through reading and through research conversations with participants. Eight participants were interviewed through the course of this study and this provided a rich source of material through which understandings and meanings could be explored. The theoretical congruency of the phenomenological approach and my personal world view provided the framework through which this material was interpreted. Keeping a reflexive journal throughout this study helped to recognize and name personal assumptions throughout the interpretive process.

Methods of Data Generation

Data for this study was generated from three sources: 1) personal interviews; 2) demographic data collection forms; and 3) a reflexive journal was kept by the researcher throughout the research process.

Interviews

In depth interviews provided the primary method of data collection used in this study. Oncology nurses participated in a single, face to face, audio recorded interview that on average lasted 90 minutes. The conversation generally began with one or more

general questions designed to illicit discussion (see appendix E for a sample of questions that were designed to initiate discussion). In keeping with phenomenological methodology, further questions were inspired through conversation with the participant. As such the conversation tends to ‘go where the participant takes it’ to make new discovery in understandings of the experience. In other words, this approach requires that the researcher assume a reflective stance of unknowing. Nothing is assumed or taken for granted. The researcher is conceptualized as an instrument of inquiry and is called to set aside ‘what you think you know’ about the phenomenon to discover what is truly being said in the conversation (Bergum, 1989). In keeping with this research approach, conversations with participants in this study frequently lead to topics that were not anticipated in advance. These ‘diversions’ frequently resulted in new understandings or perspectives that might have otherwise not been considered.

Understanding participant’s context

Demographic data is often collected to illustrate characteristics of the study population and contribute to the reliability of the sample or generalizability of the findings. The intent of gathering demographic data in this study is not to achieve this purpose, but rather, it is sought as another means of illustrating the context of each participant’s lived experience. As part of this study, nurses were asked to provide information about their years of nursing practice, work experience, educational preparation, specialty certification and previous professional experiences with palliative care (See Appendix F). Participants were asked to complete this information following the interview.

Demographic data collected for this study revealed that participants in this study have extensive general and oncology nursing experience and the majority have worked in outpatient cancer centers for years. All participants in this study are female and range in age from 30 – 53 years with the average age being 44 years. The average years of experience participants have working as a registered nurse is 20.75 years with a range of 7-34 years. On average, participants have spent 9.4 of those years working in an outpatient cancer treatment setting. The majority (6 of the 8 participants) have worked in roles where they have either: coordinated care, administered treatment or worked in a blended role that incorporated elements of each. In terms of educational preparation, four participants have graduated from a registered nursing diploma program, two completed a baccalaureate degree in nursing and two hold masters degrees in nursing. Five of the eight participants have completed post basic or specialized oncology training and / or have obtained certification in oncology through the Canadian Nursing Association. Three of the eight participants have completed post basic or specialized palliative care training and / or have obtained certification in hospice palliative care through the Canadian Nursing Association. The majority of participants in this study also described having experience in oncology and palliative care through other aspects of their career, either through representation in professional associations, personal experiences with loss or with palliative care services, teaching opportunities through the university, or caring for palliative or oncology patients in other settings (ER, ICU, medical units, home care).

Reflexive Journal

The perspective that a researcher brings to a qualitative inquiry is part of the context of the findings. In keeping with the philosophical underpinning of the

phenomenological approach, the researcher is called to critically reflect on emerging understandings and how these understandings have been generated. A reflexive journal is a valuable tool for the researcher to be attentive to and conscious of the cultural, political, social, linguistic and ideological origins of one's own perspective and voice as well as the perspective and voices of those one interviews (Patton, 2002). Engaging in critical reflection and reflexive journaling was used within this study as a means to record my personal thought process and clarify understandings as they emerged from the text. This helped to ensure the integrity of this research. It served to document decision-making points and personal assumptions and observations throughout the processes of gathering material and interpretation. Munhall (1994) asserts that this practice adds to the 'reasonableness', 'revelations' and 'responsibility' of the study (cited in Mackey, 2007, p. 562-563). That is to say it helps to ensure congruence between the steps taken within the study and the underlying philosophical assumptions of the research approached (reasonableness), document new understandings as they emerge in dwelling within the data (revelations) and preserves the authentic representation of participant language and meanings (responsibility) (Mackey, 2004). Documenting decision points and critically reflecting on my personal assumptions and observations helped to make these decisions explicit in my interpretation of the material and ensured that the steps taken throughout the inquiry were in keeping with the philosophical assumptions of the phenomenological approach.

Interpretive Process

As described earlier, the intent of phenomenological text is to allow the reader to suddenly 'see' a phenomenon in a way that resonates with their personal experience

while revealing new insights or understandings. Munhall (2007c) describes the analysis process as a complex ‘back and forth’ engagement with the material where the researcher simultaneously reflects upon the experiences and expressions of the individual and possibly, that of others engaged in the experience, and the context of that experience (i.e. the emergent situational contexts, day-to-day contingencies and life-world of the participant). Through this engagement or ‘dwelling’ within the data, the phenomenological researcher ‘lives’ the question and begins to ‘see’ connections and new understandings in the world around them. These existential understandings enrich the interpretation and analysis of the individual’s particular experience. The researcher builds these understandings into an interpretation or comprehensive expression of meaning drawing upon thoughts, emotions, statements, motives, metaphors, examples, behaviours, appearances and concealments, and voiced and non-voiced language (Munhall, 2007c).

The interpretive process in this study involved intense engagement with the data. Audio recorded interviews were reviewed and personally transcribed as part of this process. In listening to the data, reading transcripts, and the continual process of writing and re-writing, impressions about what the material was saying (or not saying), and the context of hidden and at times conflicting tensions began to emerge. Tensions that were felt within the text and the meanings associated with the experience were constructed. As patterns arose, notes are taken and the material was organized in a way that conveys the details, context and tensions of the story being told. A simple word processing document was used to note common patterns as they emerged from the text of conversation held with each participant. With each conversation a larger understanding of oncology nurses’

experience providing non-curative care began to emerge. These understandings and the tensions inherent within them were then organized in themes in the “re-telling” of the multifaceted experience. In keeping with the phenomenological approach used in this study, it is important to note that these ‘themes’ are not presented as a categorization or theorization of the experience, but rather as a means of organizing and sharing the story in a way that emphasizes the complexity of the lived world.

Integrity

I used several strategies to ensure the integrity of the research process. Above all, my primary strategy has been to design and conduct the study in such a way that is congruent with both my world view and the underlying philosophical tenets of the phenomenological approach. Through the process of immersion, self reflection and learning about phenomenological philosophy, I worked to ground myself within this perspective so that all aspects of my work could take place through this way of being. As mentioned previously, this included keeping a reflective journal and continually reflecting upon my personal preconceptions and understandings. It involved engaging in ‘reflexive presencing’ as described by Doane (2003) and an abandonment of my own issues and concerns in the conscious intent of ‘being’ with another in conversation. This ‘way of being’ continued through engagement in the material that formed the analysis so as to truly represent the understandings and meanings of the participants. As mentioned previously, this process adds to the ‘responsibility’ and ‘raised consciousness’ of the study in ensuring that interpretation reflects both the meanings of participants while revealing hidden tensions and new understandings about the phenomenon (Munhall (1994) cited in Mackey, 2004).

I also kept an audit trail that describes the steps taken throughout the inquiry and a rationale (informed by my understanding of the phenomenological approach) for each decision made throughout the research process. As mentioned previously, this adds to the ‘reasonableness’ of the study (Munhall (1994) cited in Mackey, 2004). Further the process of discussing these decisions and sharing early writings of the emerging interpretation with project supervisors who have experience conducting research using a phenomenological approach contributed immensely to ensuring the integrity of this inquiry.

Phenomenological inquiry offers an opportunity to reveal what was previously concealed and perhaps taken for granted in nursing practice. This study revealed meaningful understandings about the inherent complexity of oncology nurses’ practice when providing care to patients and families receiving non-curative treatment for advanced cancer. In the following chapter, these understandings will be explored in greater detail. Ultimately, findings that have been generated through this process offer a valuable new contribution to ongoing discussions about how a blended approach to providing both palliative and cancer care might be supported in clinical practice.

Chapter 4

Interpretation: Coming to an Understanding

As mentioned in the previous chapter, the process of interpretation or ‘coming to an understanding’ was guided by the tenets of phenomenological inquiry and evolved as a back and forth immersion in the audio recordings of conversations with participants and transcribed records while consciously reflecting on (and questioning) what I was hearing and what this might mean. Each conversation was interpreted as its own understanding – a snapshot in time of the thoughts, feelings, perceptions, struggles and rewards the oncology nurse experiences in her daily work while caring for people with advanced cancer who are receiving non-curative treatment in the outpatient ambulatory care setting. As each understanding took shape, a larger picture of how oncology nurses experience providing non-curative care emerged. The following section is organized using the salient themes and sub themes that have emerged from the data. To be clear, these themes are not used to generalize or create a homogeneous story describing nursing experience, but rather as a framework that captures the hidden complexity of practice and the tensions inherent in their work.

Major themes arising from this work include:

1. ‘Safe Harbour and Defensive Nursing’: A discussion of how oncology nurses think and feel about the role they have providing comprehensive cancer care to patients and families living with advanced cancer.
2. ‘Balancing Hope and Miracles with Honesty and Witnessed Suffering’: An exploration of competing internal and external tensions oncology nurses

experience when providing non-curative treatment and care to patients and families living with advanced cancer.

3. 'The Safety Net': A discussion about oncology nurses' experiences in 'working the system' to reduce patient and family vulnerability while receiving non-curative treatment.
4. Staying in touch and letting go: A discussion about how oncology nurses experience the sharing or transition of care and cumulative loss.

Safe Harbour and 'Defensive Nursing'

Although the nature of the therapeutic relationship that is established between an oncology nurse and a patient and family is not exclusive to the experience of providing non-curative treatment and care, it is pivotal to understanding how the oncology nurse understands her role in protecting the emotional and physical safety of patients as they transition towards end of life. Oncology nurses often develop a close relationship with the patients and families they care for over time. They bear witness to the 'ups and downs' of the family's cancer experience and in building relationship come to learn about the patient's story – stories of their families, their hopes, their lives before cancer and their lives with cancer. In becoming a part of this story, oncology nurses speak of the sense of honour and privilege of providing care and equally, the sense of responsibility they have to ensure that families receive the care they 'deserve'.

Participants frequently spoke of the sense of personal responsibility they feel in making sure that all patients and their families receive quality care. This sense of responsibility seems to be part of the greater call that oncology nurses have to 'be there' for patients in their care and begins early in the relationship that they establish.

I take ownership of the patients the moment they become mine kind of. Um, that sounds so possessive! But if I've had a patient a week, or I've had a patient five years, the need is still the same... I think that sense of responsibility kicks in right away. Yeah, that kicks in pretty fast. (Participant 1)

This sense of personal responsibility seems closely linked to the oncology nurse's identification of self in the situation of another. In choosing situations to share, participants commonly spoke about the patients that 'stood out' for them or the ones that hit 'close to home'. These personal connections seemed to arise with the recognition of common ground – seeing oneself in the situation of another - whether it be because the patient was a similar age, had similar interests or similar family commitments.

You get to know (patients and families) on a... personal level to some extent... When it's somebody that is connected to you it makes it more real and makes it harder. (Participant 3)

Further, the language chosen by participants when describing moral angst or tensions they perceived between what 'ought to be' when compared to 'what is' suggests that oncology nurses often 'put themselves in the patient's shoes' to set the standard of the care they aspire to provide. Many excerpts from the transcripts include phrases like "if that was my family member" or "if that was my mom, I would want..." when framing the care they believe patients ought to receive as they transition toward end of life.

The experience of personal ownership or of having patients 'belong' to a clinic or 'belong' to a nurse seems to be shared by patients and their families as well. When needs arise, patients and families seem to turn to 'their' oncology nurse as their first source of support. Participants commonly spoke of being that connection for patients – the trusted source they would turn to when they needed information or support, even when care had transitioned to other services.

We get people phoning our clinic even when they are patients in the hospital...they're calling from their rooms! (Laughter)...People just feel like it's like an ownership. Like that's my clinic, that's my doctor, my nurse is there, they know everything. So it's that security. (Participant 2)

Or (patients) call you from a palliative bed... "You know a doctor was just in here and he's going to do this and this and this, what does (the oncologist) think?" (Laugh)...they've just been that special. You know, we're family. (Participant 4)

Some participants described how this sense of personal responsibility and commitment can lead to personal sacrifices to ensure that their patients receive the care they require. The excerpt below provides an example of how oncology nurses may go 'above and beyond' to ensure that patients receive the support they need.

I'll step out of my comfort zone to advocate for them, I'll stay late if I have to, I've run prescriptions over to (a community pharmacy) myself so that drugs can be delivered for them and everything.... I have never yet left for lunch on a clinic day – ever – in nine years... And that's not the exception; there is not a nurse who works in (outpatient cancer clinic) who wouldn't do everything they could within reason. Now it's a little unreasonable to be dropping off patient's prescriptions, and that hasn't happened often, but it's happened! (Participant 1)

Tensions exist within this description of the oncology nurse's commitment to providing comprehensive cancer care. Many participants spoke of this willingness to go 'above and beyond' in the care of a patient as though it was expected or presumed to be part of the natural role of being an oncology nurse. However beneath this is the subtle recognition that at times it is 'unreasonable' to make some of the sacrifices that oncology nurse do in the interest of patient care. Despite this, there seems to be a sense of resignation that these sacrifices are required to maintain the quality of care that the nurse aspires to provide.

Although there seems to be the common assumption that oncology nurse colleagues practice in the same manner, the experience of feeling personally responsible for a patient's care and safety was sometimes described as a large responsibility to

shoulder alone. In the context of a busy clinic or busy treatment floor, several participants expressed feelings of angst with the thought of not having the required time, space, or privacy to care for patients who are receiving non-curative treatment in a way that attended adequately to their physical or emotional safety. Although participants acknowledged that did not perceive themselves to be alone in feeling this way, they expressed feelings of isolation recognizing that there is limited help they could draw upon when called to juggle the competing demands of the various needs at hand.

I feel very overwhelmed...I'm just waiting for a critical incident to happen because you can't be everywhere when you're needed. It's a huge, it's a staffing issue. And um, it concerns me. (Participant 7)

And sometimes I have three doctors all running clinic at the same time...sharing the same space, the same nurse, and you're expected to pick up. There is no resource to call upon – like “you're it baby”. (Participant 1)

One participant equated this sense of personal responsibility with defensive driving describing a sense of heightened vigilance in protecting patients and families who are vulnerable as a result of living with advanced cancer and its treatment.

I think I nurse defensively like I drive defensively. When I did my driver's education course... the instructor said “Drive as though everyone out there is stark raving mad and you have to protect yourself from death at every moment” and I think I nurse the same way! “Take care of that patient like everyone out there is out to get them and make sure that they are going to be looked after.” Isn't that awful? (Laugh)... Just don't pass the buck. Like, make sure it's done – don't expect someone else to pick up, to catch it. Like if it's going to fall through the cracks, you might be the only person there to catch them from falling through the cracks – so do it. Yeah. (Participant 1)

The image of ‘defensive nursing’ serves as a powerful metaphor to how some oncology nurses may position themselves in the provision of care to patients living with advanced cancer. The ambulatory cancer treatment center is conceptualized as a ‘safe zone’ because the oncology nurse trusts that colleagues are equally vigilant in ensuring

that patients receiving non-curative treatment will receive the care that is consistent with their shared philosophy of care. However, some oncology nurses also express feelings of isolation in that role and personal distress in situations where the context of the work environment (limitations in time, space and privacy) or limitations in services outside the ambulatory care setting, constrains their ability to provide care in a way that adequately attends to the patient's physical and emotional safety. These feelings of distress are heightened in situations where patients receiving non-curative treatment are required to seek medical attention outside of the ambulatory cancer center environment, particularly when outside health care providers are not perceived to share the same level of vigilance in attending to the patient's emotional and physical vulnerability.

These understandings are key in laying the foundation for understanding how oncology nurses describe the experience of providing non-curative treatment; particularly in situations where oncology nurses are witness to the mounting burdens patients experience as a result of either ongoing non-curative chemotherapy treatment and / or disease progression and patients become more vulnerable to the risk of developing crisis in the community.

Balancing Hope and Miracles with Honesty and Witnessed Suffering

Everybody has the right to hope for a miracle, but you don't want them to be blindsided when things go wrong, so it's a balancing act. (Participant 5)

Oncology nurses seem to balance two simultaneous objectives that can sometimes be in odds with one another in their vigilance to attend to both the emotional and physical safety of patients receiving non-curative treatment. On the one hand, the oncology nurse seeks to preserve and respect their patient's hope for prolonged survival with continued

non-curative treatment, and on the other, oncology nurses struggle to ‘keep it real’ by revisiting treatment decisions in the context of witnessed suffering and trying to construct a ‘back up plan’ to rescue patients should they run into crisis in the community. Within each of these objectives lie inherent tensions that are shaped by the various conceptualizations of how both cancer care and palliative care are understood, how treatment decisions are framed within their care team, and services available within the community. The following sub themes will be used to guide discussion about the inherent tensions within the experience of balancing hope and miracles with honesty and witnessed suffering:

1. Hope and Miracles: ‘Who am I to say?’
2. Hope and Miracles: The evolution of cancer as a chronic illness
3. Hope and Miracles: ‘the right to fight’
4. Honesty and Witnessed Suffering: ‘Testing the water’ with ‘control’ language
5. Honesty and Witnessed Suffering: ‘If they only knew...’
6. Honesty and Witnessed Suffering: Vulnerability and Advocacy

Hope and Miracles: ‘Who am I to say?’

As long as the patient’s on treatment, somehow the patient and the family still have hope. And that’s why they can’t stop it. (Participant 3)

The theme of hope recurs often in the language that oncology nurses use to describe decisions patients make to start or continue with non-curative treatment. Hope is often equated with ongoing treatment and discussions exploring the possibility of stopping treatment seem to be fraught with concerns of ‘taking away’ the person’s hope. The concept of the ‘miracle’ seems closely related to this understanding of hope.

Participants frequently spoke of situations where they thought the non-curative intent of treatment had been clearly discussed with patients and families throughout treatment but were surprised to find that the family had not shared the same understanding when treatment failed. Some participants framed this disconnect in understanding as perhaps the ‘hidden’ expectations that patients and families may harbour hoping that they will be the miracle.

I don’t think (patients) understand that the cancer they have is terminal. You know, they know their doctor is treating the cancer and... I think that to some extent they still think there’s a possibility of cure. (Participant 6)

Some people just don’t hear (that their cancer will not be cured with treatment). They hear it, but they’re not taking it in... They may hear you say it but in the back of their head they’re thinking “Yeah, well miracles really do happen”. (Participant 3)

The experience of miracles forms part of the discourse for oncology nursing staff as well, particularly when trying to balance hope with witnessed suffering. It seemed like each oncology nurse interviewed had a story to tell of the patient who surpassed all expectations.

I had another man...we didn’t give this man much hope at all...He looked dead when we first met him. And we just thought “Oh, this man is not going to do good, like he’s not going to respond to treatment” and I think he lived two years? With treatment. And so he was always our miracle. (Participant 3)

I remember one man in particular (nurses on the ward) wanted to do palliative papers. In fact, looking at him, I would have done palliative papers! (The oncologist) was the one who said “NO! We’re starting treatment” and I was concerned... he looked horrid. (The ward nurses) thought we were nuts. I didn’t tell them I thought so too! But we gave him that one treatment and that man became a new man within a couple of weeks...And now he’s in complete remission... spending his winter down in Arizona. So you never know. You never know. They teach me something all the time. (Participant 4)

The experience of the miracle was often described as a humbling one. It seems that in bearing witness to the miracle, oncology nurses are reminded to check their

assumptions about the futility of treatment, even when it seems as though the treatment is likely to do more harm than good, out of respect for the patient's hope for a miracle and the recognition that miracles do happen.

I don't know if any of us would be comfortable with stopping treatment when a patient wants to continue. And we're not God. I mean, I couldn't. I would not. That man...seeing him after his surgery? I think my attitude was "I don't even know why we're doing treatment on this man. He's so sick, there's no way he's going to be able to survive chemo...and he lived a good life for two years. So I think we always have to be humble. We always have to remember that cancer is just one part of the person, their will to live and their inner stamina also plays a part in that. (Participant 3)

There are several competing tensions that seem to exist within the experience of witnessed miracles. On the one hand, being witness to the miracle reaffirms the value of non-curative treatment. These successes are measured by providing years of life and control of symptoms for the patient, but also perhaps in reaffirming the personal success that health care providers experience in their efforts to control the disease.

However, it would seem that the experience can also be paralysing in several ways. First, it seems that the possibility of miracles adds a layer of uncertainty to the predicted course of the illness and makes planning for end of life difficult. Closely related to this is the sense that oncology care providers (including oncology nurses) ought to remain neutral when presenting treatment options to patients considering non-curative treatment because of the possibility of being proven wrong. Oncology nurses often spoke of defaulting to a 'who am I to say' position when decisions to pursue ongoing non-curative treatment conflicted with their personal or professional opinion that further treatment was likely to cause harm. In checking their assumptions about the futility of treatment, nurses also seem to check their feelings about whether or not they ought to weigh in on the decision made by the patient. In essence, there seems to be the

assumption that in making the decision not to offer treatment in the context where treatment is more likely to cause harm than benefit, the health care provider is in some way ‘playing God’ and possibly depriving the patient of the possibility of their miracle.

Patient expectations of miracles can also be difficult for oncology nurses to witness, particularly in situations where patients are perceived to be suffering while ‘holding out’ for another miracle. In such cases, participants described how previous ‘miracles’ experienced by the patient and the expectation that the next miracle may be just around the corner can inhibit acceptance of end of life and perhaps prevent the patient / family from ‘putting the cancer away’ and focusing on ‘quality of life’. The following quote is a continuation of the story that Participant 3 shared about the gentleman who appeared ‘dead’ when they first began treatment and who went on to survive two years with treatment, contrary to staff expectations.

He stayed on treatment. He would never stop treatment and he was waiting for...approval for a third line drug. And he died waiting for the approval. And because he would never, and I mean we quite bluntly said “Why don’t you go palliative? You might not even be accepted for this drug!..But he would not to palliative...“No I’ll wait for the drug”. And he was sick. (Participant 3)

Hopes that are perceived to have been ‘unrealistic’ can be a difficult emotional burden for oncology nurses to carry with them when they feel that they were in some part responsible for misleading patients in those expectations.

You don’t want to make promises that you know are not going to be true. So this is a very hard thing when people see you as a place that’s supposed to cure their family and you can’t do it... You always hope for the best but you sometimes feel like maybe somewhere along the way we’ve mislead this person. (Participant 5)

Hope and Miracles: The evolution of cancer as a chronic illness

We can’t cure it, but we can help control it. You know, your diabetics are on insulin, that’s not a cure, it’s a control treatment. Heart disease, you’re on

medication. For your cancer you're on chemo. It's just that you can't be on chemo forever. (Participant 2)

Advances in cancer treatment have resulted in prolonged survival. Where for some diseases time at diagnosis had been measured in months, with treatment time may now be measured in years. These successes have changed the landscape of advanced cancer care including how advanced cancer is understood and how it is treated. The growth of second, third, fourth and fifth line treatment options have extended the opportunity to continue with non-curative treatment in a way that did not exist before.

(Cancer treatment) has certainly changed over the years... twenty years ago...if A and B didn't work, there was palliative care. Now we might get up to letter F or G and say, OK, how nothing's definitely not working this time so it's time to (quit). (Participant 8)

Although these advances do not cure the disease, they can prolong survival for a length of time. While this is celebrated, it can add several layers of complexity to the care that oncology nurses provide. In the quote below, a participant reflects on how advances in non-curative treatment have prolonged survival but also added to the frailty and vulnerability of the patient living with advanced cancer. This in turn, adds to the complexity of care in the outpatient cancer setting.

The treatments themselves have changed and now the acuity of the patients are getting much more intense at times. They're living longer, which is great, but it affects also at the same time the rest of the spectrum...they're much more acute... they now have not only their symptom problems, but also toxicities from their previous treatments that you have to deal with as well. Patients are just very acute walking through those doors...it's not so black and white anymore. (Participant 7)

In addition, participants often spoke about how they are uncertain from one patient to the next, what may be offered next as a treatment option when the current treatment fails. Although oncology nurses often continue goals of care discussion on an

ongoing basis with patients and families, they may not always have a clear sense of the road ahead when counselling their patients.

(The oncologist) usually deals with that stuff because we don't always know what the next treatment is going to be... It's really hard to keep up with all of this stuff. And sometimes what we think might be the next treatment that (the oncologist) might try isn't. (Participant 3)

This uncertainty about possible future treatment options seems closely related to previously described tensions about hope and miracles. Participants in this study spoke about how societal perceptions of cancer advances can raise expectations for treatments that may not always be available or appropriate. In speaking of this, nurses expressed concerns about how these expectations can fuel patient's hopes in a way that may be unrealistic.

There's all these new treatments...I've had patients pass away in the last year that have primary cancer in their brains, well "why don't they get the gamma knife? ...they just don't realize that it's not the treatment for what their family member has... they just hear "oh, this works on tumours in the brain" (Participant 5)

The internet and online access to health information is perceived to complicate these raised expectations simply because patients without a medical background may not understand the medical terminology used to describe the 'fine print'.

Patients love information, like the internet, and try to find the latest. They don't read the fine print so they don't realize that you have to have this type of disease to even qualify. You know with cancer patients like the leukemics, they all seem to think transplant is the cure but it all depends on cytogenetics – which if you're a lay person, what's cytogenetics? (Participant 5)

In keeping with earlier discussions about the sense of personal responsibility oncology nurses have in ensuring the safety of patients living with advanced cancer, some participants spoke of the sense of personal responsibility, or personal sense of failure they experience when the treatment fails. This seems particularly strong in the

context of advances in cancer treatment. It seems these advances, and perhaps, the raised expectations for better outcomes may be experienced as an emotional burden by oncology nurses who feel that they have ‘failed’.

It’s hard on use because you’re trying to do your best and you feel like you’ve let (patients / families) down...(families) think “Well, why couldn’t you have done more?” Like there’s been so many changes in this and that, it’s like “How come it didn’t work for my family member?” So it’s hard. (Participant 5)

One participant expanded on this discussion about feelings of failure when the miracle of cancer treatment advances fail. In the quote below, an oncology nurse describes a conversation that she had with a patient who was angry and had ‘raged’ against the news that her disease had progressed while receiving non-curative treatment. This quote is a powerful illustration of how both the patient and the oncology nurse can internalize feelings of failure when non-curative treatment is no longer effective in controlling the disease.

When (the patient) was done she just sat there and she says “I feel a failure”. That *she* felt a failure. You know, and I remember thinking “I feel the failure! We failed you!” ...That’s something that I think we still have to work through here. Because when patients don’t survive, we do feel responsible. (Participant 4, emphasis added)

Hope and Miracles: ‘the right to fight’

“Well, everybody’s got to do it their own way”. You know? Some people have a lot that they want to live for and so they’ll just keep fighting and fighting and fighting. (Participant 6)

The use of battle language seems to be deeply embedded and perhaps, not always consciously recognized within the cancer treatment experience. In discussion, participants commonly referred to chemotherapy treatments as ‘regimens’ or ‘regimes’, treatment was sometimes framed as a ‘battle for control’ and patient decisions to continue

with non-curative treatment are often equated with a desire to 'keep fighting'. However, when asked about their personal understanding of the intent of treatment in the context of advanced disease, participants were often deliberate in their choice of words to avoid framing cancer treatment as a battle when discussing the intent of non-curative treatment with patients. 'Battle language' was often perceived to make conversations that much more difficult when treatment fails and some described how use of this language can place a large burden on patients to 'keep fighting'.

(Framing cancer as a fight) puts a burden on the patient; to continue to try and fight despite the toxicities of the treatment if they are experiencing them...I don't tend to approach it in that manner. Because that's a heavy burden to put on somebody I think. Everybody can, you know, tolerate only so much. (Participant 6)

Having said this, participants spoke of understanding 'where patients are coming from' when they were not prepared or unable to 'give up the fight' and discontinue non-curative treatment despite the growing burden of progressive disease and treatment toxicity. In particular, oncology nurses seemed to identify with younger patients with young families who were not ready to 'let go' of treatment and respected the patient's wishes to 'keep fighting'. As mentioned previously, participants often identified with patients facing decisions about whether or not to continue with non-curative treatment by 'putting themselves in the patient's shoes'. In such circumstances, it seems that oncology nurses are able to justify the desire to continue non-curative treatment, particularly when the patient is young and has so much to live for. The following story of a young mother who made the decision to continue with non-curative treatment even though it was clear that the treatment was no longer helping is a powerful illustration of this.

And she said... "You know I can't stop treatment" and I said "I know" and I didn't cry when I told her - I said "I know, you have two little boys, and if I was in your

position, I would do exactly what you're doing, because you have two little boys to live for and I would fight every moment that I was alive. I would fight.” (Participant 3)

Inherent within this ‘right to fight’ seems to be tensions about balancing when ‘not to fight’. Participants often spoke of the respect that they have for patients who decide that the burden of non-curative chemotherapy and the negative impact on their quality of life is not worth ‘the fight’.

The ones that have the most common sense, you know the elderly, they say “No! I don’t want this! Why do I want to come here every two weeks and go home with chemo?” You know, I admire those patients. It’s like Yeah! Why would I want to put up with this? (Laugh)...But that’s not everybody. There’s a lot of elderly people that want to fight this too. (Participant 2)

Oncology nurses tended to frame the decision not to fight as admirable, particularly in circumstances where the patient was older and valued quality of life over quantity of life. This seems closely connected to the feelings of angst participants described when patients who seem to be particularly frail and vulnerable (namely the elderly) decide to pursue non-curative treatment. In such cases the burden and toxicities of treatment were viewed to compromise the safety of older patients and discourses about quality of life become paramount. However, despite these concerns, and in keeping with the desire to remain neutral when presenting treatment options to patients, participants consistently upheld the belief that everyone has the right to choose how they approach living and dying with advanced cancer regardless of age. This comes with the recognition that quality of life is in the eye of the beholder.

When they’re older and they want chemo and they want everything and you’re looking at them going ‘Why?’ Because I’m thinking “Why would you want (chemo)? ... “Oh, quality of life!” You know? “You’re in your late 80s, why not enjoy each day to the best it can be?” and that’s when I have to learn that this is quality of life for her. It’s not my decision. (Participant 4)

As mentioned previously, beliefs about the patient's fundamental right to self determination in deciding whether or not to pursue treatment adds a layer of complexity when thinking about the role that oncology health care providers have in counselling patients about whether or not to pursue non curative treatment in the context of their particular circumstances. The unpredictability of response to treatment, the advances in cancer treatment and possibility of miracles, and the recognition that quality of life is subjective and different for each person can cause oncology nurses to reconsider their personal assumptions about the value of treatment and adopt a neutral stance in presenting options. However, conflict seems to arise when this position is challenged by health care providers outside of the cancer setting.

When you go up to the ward, you get comments like "Why are you giving them chemo? Just let them go!" Well, chemo does work. You know, it really does work. It does have good qualities to it. We have a lot of successes. But unfortunately the ward only sees the really sick ones. (Laugh) ... They don't see the ones that come in here for clinic and are doing well and are stable. (Participant 4)

Participants commonly spoke of having to defend the patient's right to choose to continue non-curative treatment with health care providers outside the cancer community. Most commonly, oncology nurses described tense relationships with ward or emergency room staff that often do not seem to share the view that non-curative chemotherapy can offer benefit. Within this experience, oncology nurses described the stigma they perceive that their patients face when seeking help outside the cancer center and the judgments that oncology nurses face about not having prepared the patient for end of life. These tensions will be explored in greater detail when discussing the "safety net" that oncology nurses work to assemble to rescue vulnerable patients from 'falling through the cracks' in times of crisis. However, one wonders if judgments about the futility of non-curative

treatment held by health care providers outside of the cancer care environment are cast because they are not commonly witness to ‘the miracle’, but rather see patients in crisis when the treatment toxicities or progression of the disease itself become overwhelming.

Honesty and Witnessed Suffering: ‘testing the water’

And as an oncology nurse you have to go with that...intuition, that gut feeling, like this is right. This is the right time, you know? ... You just have to take those conversations when you get them. (Participant 2)

Although the experience of hope and miracles may challenge oncology nurses to take a neutral stance in presenting non-curative treatment options, this does not imply that they are silent in the process of a patient’s decision making. In fact, oncology nurses describe having a prominent role in ongoing discussions evaluating goals of care with patients receiving non-curative treatment. Participants frequently described how they would ‘test the water’ with patients and families with each visit to the clinic to gauge patient perceptions about the value of continuing treatment as a means of assessing ‘readiness’ to discuss the alternatives. If oncology nurses perceive cues from the patient or their family that the burden of treatment is becoming harder to manage, or an interest in discussing alternatives, they will readily take that opportunity to re-evaluate goals of care.

Lots of times, I’ll bring that up. I’ll say, like, "Are you still wanting to come in for these transfusions every three days?" Do you still want to be doing these platelets? Or are you looking for us to give you an opportunity to say “I’ve had enough... I sort of play it by ear that way. (Participant 1)

The experience of ‘testing the water’ and the language that oncology nurses use to explore a patient’s understanding and expectations for treatment seem to be heavily influenced by tensions inherent in the conceptualization of advanced cancer as both a

terminal illness and chronic illness that can be controlled. While the non-curative or terminal nature of the illness is implicitly understood within the cancer community, the approach to managing or treating the disease is often guided by understandings of cancer as a chronic illness. The emphasis throughout the course of treatment is to control the disease for as long as the disease responds and the patient tolerates the treatment. As with other chronic illnesses, the cancer becomes ‘palliative’ or terminal when it becomes clear that current non-curative treatments are not working or the burden of progressive disease and treatment toxicities make pursuing further treatment difficult. It seems that in ‘testing the water’, oncology nurses are challenged to re-visit both the non-curative nature of the illness and the patient and family’s perception of ‘quality of life’ using the language of control.

It seems that different participants had different feelings about taking up the ‘cancer as a chronic illness’ discourse and language of ‘control’ when testing the waters with their patients. For some, this understanding seemed to naturally fit with their personal views about advanced cancer and the intent of non-curative chemotherapy. One participant challenged the very idea of ‘palliative intent chemo’ because in its essence, “chemo is just chemo” and cancer is really no different than any other chronic disease.

For many, many (cancer) diseases there’s not a hundred percent cure rate...most of this is we’re aiming at disease control. If we can get better than that, that’s great. But there’s so few, there’s so few that we can say it’s a hundred percent curable, that to me, we’re all just doing the best we can to keep this at bay...Some do well and some don’t. (Participant 8)

However, the use of alternate language may not always feel comfortable for the oncology nurse, particularly when there is concern that the intent of treatment and the life limiting nature of the disease may not be fully understood by the patient and their family.

Some participants raised concerns that the ambiguity or vagueness of ‘control’ language may inadvertently give the impression that the illness can be cured.

(Some oncologists) say we're going to do this, this, this and this, and you know, hopefully this will stop the cancer. They don't say that they can cure it, but they, you know, they're giving the impression almost that sometimes they can... What they're actually mean is, it can slow down the cancer, but they can't get rid of it. And I don't think people quite understand when those discussions occur.
(Participant 6)

However by the same token, participants noted that there is an art to giving ‘bad news’ and explicit language about the non-curative nature of the disease may not be always be what the patient wants or is ready to hear.

Some physicians are very black and white about things...and sometimes that's very upsetting for the patients when the physician is that way...It's hard to know, you really have to assess the individual about where they're at and how much information they're willing to hear on any given occasion. (Participant 6)

Although participants recognized that patients and families can ‘take away’ different messages than what may have been presented by the oncologist, some questioned if this was attributed to the communication style of the oncologist they work with, and the degree of candour used in discussing the non-curative nature of the disease at diagnosis.

Our oncologist doesn't like to use the word "palliative chemotherapy" but I think it would help if (the oncologist) would use that word more often. (The oncologist) doesn't want to...let our patients take away that hope. So as their disease progresses, they want to know ok, what's the next step, what's the next step? And you know (the oncologist) always says “well there's something, you know, like I have something to offer you”. (Participant 2)

The quote above illustrates how the language of control can provide hope and perhaps raise expectations that despite progressive disease and the growing burden of treatment, the oncologist may still have more tricks up their sleeve to control the disease a little longer. This seems to make the disappointment that much greater when treatment

fails and ‘nothing more can be done’. These tensions add a layer of complexity to the discussion about the palliative care alternative. The participant above went on to observe that when palliative care has been ‘put on the table’ early in the illness by the oncologist, she felt much more comfortable and confident as she too was able to openly discuss the palliative care alternative and supports available within the community with patients.

It’s one thing if (patients) come for (their appointment) and (the oncologist) says “OK, we’ve had that discussion, put on the palliative care program...you know it’s been discussed. But it’s hard when there hasn’t been (that discussion). That’s where it’s tricky and you have to take your cues from the patients. (Participant 2)

It is interesting to note that many participants in this study when speaking about the experience of ‘testing the water’ spoke of the communication approach used by the oncologist to frame their personal approach. In other words, early discussions with the oncologist and the approach that is used by the oncologist in framing the intent of non curative treatment seem to set the stage for how oncology nurses take up ongoing conversations about goals of care with patients throughout the course of their illness. When oncology nurses are witness to the growing burden of the disease and treatment their patients experience and it is unclear about how candidly the terminal nature of the disease was discussed or understood in conversations with the oncologists, or unclear what treatments might be considered ‘down the road’ as an alternative when current treatment fails, oncology nurses ‘test the water’ using language that has been used within the clinic (i.e. the language of control) to explore patient and family understanding of the intent of treatment and their personal goals of care.

Although the approach used by the oncologist, and perhaps more broadly, the discourse of cancer as a chronic illness sets the tone for the language used in these discussions, participants seemed to have varying styles in how they would use this

language to raise the possibility of the ‘palliative alternative’ or the eventual discontinuation of non-curative chemotherapy. Some participants described ‘floating’ the idea of altering the timing of treatment as a means of balancing the burdens or side effects of treatment with controlling the disease.

(Treatment) is every two weeks, but you know say a few months down the road you want to go to every three weeks because this is really just a control, this is not to cure. So if you have a trip to go on, do it. If you've got you know other things going on, do it... If that extra week off of chemo makes you feel better, do it! Because this is not a cure. (Participant 2)

Giving permission or control to the patient to discuss alter the timing or frequency of treatments with the oncologist was often perceived as a means of opening discussions about quality of life and having patients and families control their care. Some participants observed that patients who take this option often come to the realization that the burden of non-curative treatment is ‘not worth it’ opening the door to discussions about what alternatives may look like.

Other participants spoke of using the language of ‘treatment’ (i.e. the language commonly used within the clinic setting) to talk about the palliative care alternative.

I always tell them we have two treatment plans for you. Right now we're in the control, the next one will be palliative, and those two treatment plans are always available for you when you're ready. When you want to stop one, go to another one, we'll do it. It's your decision. (Participant 4)

It seems that in framing palliative care as another treatment option, the oncology nurse is able to raise the alternative to ongoing disease focused treatment in a way that is consistent with the language used in the clinic while avoiding language that suggests ‘nothing more can be done’.

I always use palliative care as a treatment. I always use the words “treatment plan” because that’s a word they’re used to... I want to use words they’re familiar with. So I’ll say we’re going into a different treatment plan and that’s palliative

care... We were going for control of the disease and that's not working so now we're going to put the disease away and we're moving you forward... let's concentrate on you. (Participant 4)

It would seem that even within the construct of cancer as a chronic illness, and use of the language of 'treatment' and 'control', oncology nurses have an opportunity to frame alternatives to non-curative treatment in a way that focuses on 'what can be done' when shifting the focus of treatment from the disease to the person. When thinking about previous discussions about hope, one wonders if 'palliative treatment' offers the possibility of reframing hope despite the limitations of non-curative treatment.

Honesty and Witnessed Suffering: 'If they only knew...'

It's just hard when you kind of think about how much they've suffered. You know, nobody wants to live a life when they're suffering all the time. (Participant 5)

If they only knew. If they only knew! Like do they really know that maybe this would only extend their life by two months and what those two months may look like? All those appointments, feeling awful. (Participant 2)

Participants in this study commonly described the angst they experience when they bear witness to patients and their families who are struggling to balance the hope of further non-curative treatment with the mounting burden of both the disease and the side effects of treatment. This tension seems closely linked to the sense of personal responsibility that participants expressed in ensuring the physical and emotional safety of their patients. Tension seems to mount when there is a divide between the desire to preserve hope (and shield the patient from the emotional suffering inherent in the realization that they are at end of life) and the desire to shield the patient from further physical harm from treatment.

The person's not ready but you see the writing's on the wall...I find that so hard because I don't want to take (hope / treatment) away from the patient... but (to see patients) coming into clinic for the treatments and feeling like crap... (Participant 2)

The above quote is a powerful example of how difficult it can be, personally and professionally, to witness suffering while maintaining a neutral stance and respecting the patient's right to self determination in making treatment choices. One wonders if this in some way heightens the feelings of guilt or personal responsibility that some participants described when patient and family hopes feel unrealistic and treatment 'fails'.

Participants frequently made comments like "if they only knew" when describing the angst they personally experience. Having seen people suffer, knowing how 'bad things can get' seems to heighten the angst oncology nurses experience when a patient chooses to continue non-curative treatment in the face of harm. "If they only knew" seems to capture the angst that oncology nurses experience in wondering about whether or not consent for treatment can ever be truly informed – if patients really knew how bad it could get, would they make the same choice?

You think of like myeloma patients – the ones that have had one transplant and you're offered a second – not too many go for that option of the second transplant... they already know. So sometimes you wonder if you've met somebody that's gone through it if they'd make the same choice. (Participant 5)

In thinking about this, the participant above commented on the difference there seems to be in being told about the theoretical side effects that may arise as a consequence of non-curative treatment versus experiencing them in reality.

You know that if you have radiation you might get a little bit of a radiation burn (or) GI upset...or neuropathies from certain treatments...you might get some tingling, pins and needles to your feet... but then you're tripping over your feet and you can't do your buttons up and you don't realize," I didn't think neuropathy could be that bad". You know? Or you're in so much pain that you can't walk on your feet. People don't realize that it can get that bad. (Participant 5)

Conversations about goals of care, expectations of treatment, and quality of life seem to take on a greater significance for the oncology nurse when they perceive that the patient's overall condition is worsening, be it from progressive disease or its treatment. In such situations, discussions about the side effects of non-curative treatment are used to open the door to discussions exploring the patient's perception of quality of life. Participants in this study commonly spoke about how the mounting physical burden of advanced cancer or its treatment prompts discussion about alternatives to ongoing non-curative treatment.

I don't even know how to describe it, but like I said, when you're on the floor every day and you see somebody coming in and they get this look when they're not doing well...And I mean you talk to them. They have a feeling that something's not right. (Participant 7)

Most know which is really quite interesting. "I had a feeling" they will most always say. I had a feeling something wasn't quite right or I'm not feeling as good anymore. (Participant 2)

I don't (talk about stopping treatment) on a daily basis when I see them, it's just sort of like a non-issue unless they bring it up or unless they're getting sicker and they're not realizing it (Participant 3)

Interestingly, participants in this study often commented on the 'awareness' but yet also the 'lack of awareness' that patients seem to have about the impact that treatment is having on their quality of life. It seems that subtle changes that oncology nurses perceive over the course of non-curative treatment, may not be readily acknowledged by the person who is experiencing them. It also seems to be in the context of these situations – where there is tension between what the oncology nurse perceives as quality of life (sometimes framed as 'if they only knew') and the person's continued hope or expectations with treatment (hope and the miracle) – that oncology nurses re-visit the

intent of treatment discussions to clarify the intent of treatment will all parties involved (nursing colleagues, oncologist, patient and family). These conversations become a higher imperative when oncology nurses witness suffering with treatment and growing fragility or vulnerability to the possibility of crisis.

Honesty and Witnessed Suffering: Vulnerability and Advocacy

As mentioned previously, oncology nurses bear witness to (and at times growing distress with) the growing burden of disease and treatment experienced by their patients. In the context of witnessed suffering, oncology nurses invite conversations about the burden of treatment and the patient's personal conceptualizations about quality of life. These conversations evolve over the course of a patient's treatment but become particularly important when the oncology nurse perceives that the burden of treatment becomes is becoming difficult for the patient to manage. Although participants described feeling comfortable with those conversations, they often looked to the support of the oncologist to initiate discussions when they perceived that a patient's cancer was progressing with current treatment. Participants seem to navigate these conversations and the balance their role with the role of the oncologist by 'staying in bounds' while 'clarifying options'.

It's getting that initial conversation about that change. I still feel that it's the oncologist that needs to tell (patients / families) that things are progressing and I make sure that I never step out of my boundaries and say something I shouldn't be telling them. But if I can, whatever I can do to help with understanding their disease and how we can help them. (Participant 3)

Participants expressed the need for caution not to overstep boundaries with the oncologist's role when having specific discussions about the status of a patient's cancer or the non-curative treatments that may or may not be available. Once again, the

uncertainty participants described in not knowing if other treatments would be considered, or what had been discussed previously with the oncologist seems to contribute to this sense of caution. Having said this, participants were quick to acknowledge that recognizing those boundaries and working within them did not abdicate their sense of responsibility in raising concerns or clarifying goals of care.

We're not always privy to what has been said and what's been going on. We miss that component of it. So we're not always sure but I still think we have an obligation to make sure that we're not doing more harm than good - the bottom line. (Participant 8)

I don't want to overstep bounds. But if we see them more, like if I'm the one seeing them every day then...I think my place is to phone him and say this is what I see and... this is what I think needs to be addressed. (Participant 8)

It seems that oncology nurses feel particularly responsible for advocating for the re-evaluation of treatment goals (and the cessation of ongoing treatment) when they perceive the patient to be vulnerable and at high risk for crisis. Participants in this study spoke about situations where they felt it was their responsibility to advocate for the patient and to question or challenge the offering of chemo if they believed that treatment would cause harm. In doing this, some participants appealed to their relationship with the oncologist, sought the support of their supervisor or cited the criteria of the ambulatory care setting in challenging or refusing the decision to treat.

Years ago it would not be uncommon to almost be beginning chemo on a person's death bed... But (the oncologist) has gotten a lot better...we would have guidelines and if we weren't comfortable, our nurse manager at the time would say "You know, you don't have to give this chemo because this is you. This is your license, and if you feel the parameters (are not met) or the patient is not well informed – we had that support. (Participant 2)

One time I phoned the doctor and I told him he had to come up and talk to the family and that I was really hesitant about giving chemo. And quite frankly the patient did not meet our criteria of an ambulatory care center... So I phoned him and said...first off, (the patient) does not meet our criteria...and number two, I

think it's time that you call it, you come up and talk to the family about the futility of this regime. And he did. I was surprised but he did. (Participant 8)

Sometimes ethically I have to question. Like what are we doing? ...I want (the oncologist's) rationale behind this before I give her any chemo...If I do have trouble with something, I will tell (the oncologist). You know, let's talk about this. (Participant 4)

Participants also spoke about the importance of clarifying whose goals they are meeting with non-curative treatment – the patient or the family? In situations where it is unclear, participants spoke of their sense of responsibility in clarifying the goal of care as a form of advocacy on the patient's behalf.

And with families, is this your decision or is this, the patient's decision? I want that clarified. I will talk to the patient by themselves and ask like, what, what is their goal for the chemotherapy? Where do they see themselves within this short period of time? (Participant 4)

So it would seem that despite previous discussions about the upheld values of the patient's right to self determination in defining quality of life and making decisions about non-curative treatment, there are times when the burden of witnessed suffering and growing patient vulnerability will prompt oncology nurses to abandon the 'neutral stance' in offering options and 'weigh in' on decision making. As mentioned previously, oncology nurses seem to have varying approaches in how they 'weigh in' in the conversation. In some situations a softer approach is taken where the nurse will provide the information that a patient or family might need to advocate for themselves in conversations with the oncologist, or they may take a more direct approach by either speaking with the patient and family or with the oncologist about their concerns. The approach used seems to be in keeping with the context of the situation and with the role that the oncology nurse feels that she has within the clinic in having those discussions.

I would have said “Before I give you chemo today I'm going to phone your doctor because I want him to come and talk to you...it doesn't appear that this chemo's working anymore and I don't want to be doing more harm than good to you”...but as far as coming out and saying what is your wish and you know how much more of this do you want? I'm not sure. ...I think the physician should be asking. And document and making sure cause they're the one's going to be the decision to withhold the chemo. I can't. So, I just I don't want to overstep bounds.
(Participant 8)

Despite the oncology nurse's role in 'raising the discussion' about stopping further non-curative treatment, the decision ultimately rests with the patient and the oncologist. So it would seem that oncology nurses are in some sense limited in their ability to 'protect' vulnerable patients who seem to be suffering as a result of progressive disease and treatment because the decision to stop further treatment and transition to palliative services is not really theirs to make. Oncology nurses seem to compensate for this by piecing together a safety net of supports and services in the hopes of 'catching' the patient and family if they should fall in times of crisis.

The Palliative Safety Net

As with the various conceptualizations of advanced cancer, tensions exist within conceptualizations of the meaning of palliative care. These tensions shape how nurses construct a 'safety net' of supports and services for patients living with the cumulative burden of advanced cancer and treatment toxicities as they approach end of life. For the purposes of discussion, the following sub themes will be used to illustrate these tensions:

1. Timing: When is a patient palliative?
2. Timing: Fragility and crisis
3. Timing: Judgment and Guilt
4. Holes in the net: Constraints in time, space, and privacy

5. Holes in the net: Falling through the cracks

Timing: When is a patient palliative?

The identification of a patient as a cancer patient versus a palliative patient is challenging given the tensions in how both advanced cancer and palliative care are conceptualized. While the non-curative or terminal nature of the illness is implicitly understood within the cancer community, the approach to managing or treating the disease is guided by understandings of cancer as a chronic illness. The emphasis throughout the course of treatment is to control the disease for as long as the disease responds and the patient tolerates the treatment. Advances in cancer treatment have extended the treatment options available and the opportunity to continue the pursuit for control of the disease with second, third, fourth, and fifth line treatments. The cumulative impact of this prolonged non-curative treatment path can result in cumulative toxicity and increasing complexity in the acuity of patients treated in the ambulatory care setting. This mounting ‘fragility’ of the cancer patient over the course of time with treatment makes the personal sense of responsibility described by participants to protect the patient from harm all the more powerful. As discussed earlier, these tensions leads the oncology nurse to continually ‘test the water’ to gauge the timing of transition while balancing the competing desires to maintain hope (or emotional safety) with ensuring that the patient does not run into crisis with treatment (physical safety).

Oncology nurses coordinate the transition to formal palliative care services when there has been a decision to stop further non-curative chemotherapy treatment aimed at controlling the disease. As mentioned previously, within the urban health care region, access to formal or case coordinated palliative care services is available if the patient is

expected to have a prognosis of less than six months and if their goals or expectations of care are consistent with treatment offered through the palliative care program (i.e. there has been a decision to stop chemotherapy and forgo attempts at cardiopulmonary resuscitation). Benefits to enrolment in coordinated palliative care services include: case coordination, palliative home care nursing visits, admission to resident hospice if eligible, the possibility of direct admission to a palliative care inpatient unit in times of crisis if a bed is available, and enrolment in the provincial palliative care drug access program.

In discussion with participants, it seems that the palliative care alternative is one that is offered as a consolation to patients and their families when treatment fails. This is not said to mean palliative care is presented as a lesser treatment option or as a ‘consolation prize’ but rather as a means of ‘consoling’ patients and their families – recognizing the complex needs patients and families have and will continue to have as they reach end of life and trusting care to teams that specialize in providing this kind of care. Participants interviewed in this study frequently spoke about the confidence and trust they have in the nurses and physicians who provide care through the regional palliative care program.

And you call up a (palliative care) coordinator and you say like, this is where I’m at. I know this is no warning. This is kind of an urgent situation, what can we do for this patient? And before you know it, like it’s happened where someone’s called back at the end of the day and they say we’ve got so and go going to a bed here or we’ve got a nurse going into that. So that is really cool. (Participant 1)

But once he’s in palliative, I have no...worries. I have none. None at all. Amazing program...and I know that my patients will be well loved and well cared for...So, ah yeah, I'm very proud of the palliative care program that we have in this province. (Participant 4)

Going back to earlier discussions about the personal commitment oncology nurses seem to have in protecting the safety of their patients, it would seem that palliative care

nurses are perceived to share the same level of vigilance in attending to the vulnerability of patients living with advanced cancer. There is a sense of trust in sharing care when palliative care staff is involved.

In many respects, it seems that linking to palliative care services earlier in the patient's course of advanced cancer treatment is perceived as a sort of 'safety net' by participants in this study. Palliative care services are often framed as a means of reducing the vulnerability that advanced cancer patients may experience when they are outside the 'safe zone' of the ambulatory cancer clinic and 'alone' in the community.

I can't even begin to imagine what these people go through at home... and they are away from a safe zone. When they're here, they're wonderful to us and, and we're wonderful to them. But, it's a protected environment. When they're home... I know that a lot of these people are not the same people that they are when they're here. (Participant 3)

In situations where the patient is not prepared to stop non-curative treatment, participants frequently spoke of how they would implement home care services and request that a palliative care nurse be assigned to their care. In fact, one oncology nurse joked about the lengths she would go to in ensuring that it would be a palliative home care nurse (rather than a regular home care nurse) that was dispatched to the patient's home.

So you try to get in through the, I call it the back door, but I don't think it is. Where I call home care and ask for a palliative nurse, and try to get them in that way so they know them... and I'll put down "I need them assessed for pain control once a week, just to make sure their pain is under control, what we're doing for their pain, that they're mobile" then... I'll make something up! I'll say they're falling or something just to get somebody in the house if I'm desperate. So I do, I do lie. (Laughter) (Participant 4)

The 'back door' option that oncology nurse describes above is an available alternative to making the connection with the palliative care team in situations where the

patient has decided to continue with chemo treatment and does not meet criteria for case coordinated services through the urban palliative care program.

The conceptualization of palliative care as a 'safety net' seems closely tied the angst participants expressed when describing situations where they were unable to enrol patients for case coordinated palliative care services because of the patient's decision to pursue ongoing treatment. Many expressed feeling a sense of injustice that patients seeking ongoing non-curative chemotherapy are excluded from coordinated palliative care services citing that these patients need, are entitled to, the same level of support as those who have decided to forgo non-curative treatment.

I would love to enrol (patients receiving non-curative chemotherapy) to palliative care right then so that they've got a relationship with the palliative care team...but (in the city), there's that block that we exclude people on chemotherapy. And I realize there has to be a way of excluding people, that they can't put everybody in the world on palliative care cause we're all going' in that direction (laugh). But I think if somebody's probably going to die in 6 months (regardless of attempts to control the disease or its symptoms) then we are treating the patient. If they need palliative care, then they should have it. I would like them included. (Participant 1)

This sense of injustice seems to be reinforced with the recognition that patients receiving non-curative chemotherapy in health care regions outside the urban center are permitted to access coordinated palliative care services concurrently. Participants in this study frequently spoke of the inequality that exists for patients living within the city as compared to those living in the surrounding rural area in this regard.

If you're in the city and you are on oral chemo you cannot have (coordinated palliative care). You can maybe be visited by a palliative home care nurse, however if you suddenly start failing, there will be that gap. You may have to go through emergency...you will not have the easy transition. (Participant 7)

When describing their concerns arising from this gap in services, participants often remarked that patients receiving non-curative chemotherapy were at a disadvantage

because they did not have access to the same amount of services or support at home. To compensate for this, many participants described how they would ‘work the system’ using the ‘back door’ to request home care services, and specifically, request that a palliative home care nurse be assigned to the patient’s care. What is interesting is that this ‘back door’ option is essentially the same type and amount of service that a person would receive if enrolled to coordinated palliative care services. The primary difference being that the person receiving non-curative chemotherapy would not have a palliative care coordinator assigned to their care to help them navigate the health care system or access to direct admission to the palliative care inpatient units if they were to develop urgent care needs at home.

So it would seem that the angst that oncology nurses describe when speaking about the gap in services is not so much that the patient is vulnerable in the community because of lack of palliative home care nursing support, but rather that in times of crisis, patients receiving non-curative treatment do not have access to direct admission on a palliative care unit. In essence, oncology nurses are only able to construct a partial ‘palliative safety net’ when piecing together aspects of a patients care rather than having the security of the full ‘palliative safety net’ beneath them. In the context of how oncology nurses perceive their role, and their personal sense of responsibility to ensure their patient’s safety, the construction of a ‘partial safety net’ adds to the uncertainty that a patient may ‘fall through the cracks’ if they are unable to rescue them in times of crisis.

Timing: Fragility and crisis

As discussed previously, participants in this study described how they frequently ‘test the waters’ with advanced cancer patients throughout the course of their non-

curative treatment to gauge readiness for discussions about quality of life and transition to case coordinated palliative care services. Although these conversations occur throughout the patient's treatment and may extend over a prolonged period of months or even years, participants often described a very narrow window of time between the time that the burden of treatment becomes insurmountable to the time of rapid decline and death. So despite discussions that may have evolved over an extended period, transition to palliative care frequently happens in times of crisis when the burden of treatment becomes overwhelming.

Then you kind of hit a crisis too you know? That's usually when things happen... (patients / families) have just been barely coping at home and then all of a sudden it's like the rug has been pulled out... so then it's too late! It's like let's get that support in there before shit hits the fan right? (Participant 2)

Participants spoke about how these sudden changes can come as an unexpected surprise to patients and families who had been 'doing well' just prior to the crisis. This seems closely related to previous observations that patients and their families have both an 'awareness' and seeming 'lack of awareness' of the burden of treatment.

It's like "No, no, we're coping, we're coping" until they are not... it's almost like mom and dad barely kind of see... they don't know really the full picture. (Participant 2)

However, it seems that crisis can come as a surprise to the oncology care team as well. Participants frequently spoke of the changes that can occur between clinic visits and the lack of awareness that the oncology team had of those changes at home.

If something happens in between (doctor's visits) you don't know about it if (patients/families) don't call... They are just saving up for that next doctor visit and they come to the door in a wheelchair... and then they are being admitted. (Participant 2)

Participants also spoke of the unpredictability of certain diseases that can even leave staff wondering ‘how did that happen so fast?’ It seems that even in situations where things change quickly there remains the question “is this something that can be fixed with further treatment?”

Even with us, it’s like shock. And you’re just in denial for about thirty seconds and you’re trying to wrap your brain around that that blood work belongs to that person. ...it’s like everybody’s in shock... and it’s like “Ok, is now the time to have the difficult conversation? Or is this something we can somewhat fix?” (Participant 5)

It’s tricky to know this isn’t going well... Just because we think we can still turn this around. We want to give them a chance to try to turn this around... because you just keep thinking “this is an immune system mistake! It’s got to be fixable!” And sometimes it’s not. (Participant 1)

The unpredictable nature of advanced cancer in the context of non-curative treatment can make estimates of prognosis and decisions about the timing of transition to case coordinated palliative care services a “guess.”

It’s a guess! Everything is a guess, and that’s what (the oncologist) said too...but they put a lot of credence in (prognosis). Everybody does...maybe because it’s written (on palliative care enrolment forms) and it’s not accepted if it’s over six months you know? ...so it’s about getting them something rather than using the prognosis for any other reason, cause over 6 months will go to PCH, under 6 months will go to palliative care. (Participant 4)

It’s funny when you think we’re all dying. And the six months, the magic six months. What did one (patient) say? What if I live longer than six months? And I said “Well that’s a hallelujah moment! (Laugh) (Participant 4)

In the above quote, participant 4 expresses feelings of frustration regarding the usefulness of having a prognosis when it is only a guess and jokes about the consequences if the patient lives longer than anticipated. Her observation that it is about ‘getting something’ alludes to how estimates of prognosis are used to inform disposition planning when patients living with advanced cancer are admitted on medical units or to

access case coordinated palliative care supports. This comment seems linked to general feelings of frustration that the purpose of prognostication is not so much to prepare patients for end of life, but rather as disposition leverage and deciding where the patient ‘fits’ in the broader health care system. This leads to wonder if the angst that oncology nurses describe in building a ‘palliative safety net’ for patients in the community is shared by care providers in other settings.

Timing: Judgement and Guilt

As mentioned previously, those who are witness to the ‘repetitive crisis’ may develop assumptions about the futility of non-curative chemotherapy in the context of advanced cancer. Participants frequently spoke of the judgments they perceive from health care providers outside of the cancer community that cast judgment that the transition to palliative care did not happen earlier. However oncology nurses defended the patient’s right to treatment pointing out that with existing criteria for services, there are little other options.

We often hear from palliative care “Oh, this referral came too late”. Well the patient wasn’t willing to (stop treatment) before now. So you know, that’s why it came so late. Or they present to emergency and they’re going “well why...hasn’t palliative care been discussed?” And this patient just wasn’t willing to go there...Patient wasn’t ready. (Participant 6).

A lot of times it’s crisis mode. And sometimes they get angry at us for not doing a palliative referral earlier. And you’re going “she was on treatment!” What could we have done? Like what option is there? (Participant 4)

Having said this, recognizing the rights that patients have to treatment does not mitigate the distress that participants expressed when bearing witness to crisis situations. Oncology nurses frequently described the personal distress they experienced when they were unable to set up the ‘safety net’ and link patients to coordinated palliative care

services in the context of their treatment choices. In speaking with participants, it seems that oncology nurses often attempt to manage these concerns within the cancer setting even though it is not really 'set up' to manage that kind of care. In situations where these needs exceed what can be managed in the clinic setting, participants spoke about feeling reluctant but obligated to send the patient elsewhere so that their care needs could be met.

In the treatment room, ah, if we can accommodate them we will ...we'll do what we can for them but ...if they need more acute services or...if it's close to one to one nursing, they need to be admitted. Failing that they need to go to the emergency room. As much as we all hate sending our patients to the emergency room, but lots of times if they're beyond what we're capable of doing, it's not fair to everybody else there. We're an ambulatory care center. (Participant 8)

In the absence of these options, participants frequently spoke of the emergency room as the 'last resort'. Participants in this study often spoke of the lengths they would go to in trying to avoid the emergency room citing concerns about how their patients would be received by staff, and trying to respect the wishes of patients who would prefer to avoid the emergency room at all costs.

I think I would try to do more from an outpatient basis because they don't get treated well in emergency! (Participant 1)

I hesitate sending them (to the ER) sometimes. I will say come to our department first! (Laugh) You know, and let's see if it's something where we can keep you out of there ...(but then sometimes I have to) tell them to go to emergency. And then when I get flack, I just kind of go you're an emergency! What were they supposed to do? ...Where was he supposed to go? (Participant 4)

Participants in this study commonly spoke about how the environment of the emergency room is not an ideal setting to attend to the emotional and physical vulnerability of patients and families living with advanced cancer who experience crisis as a result of progressive disease or complications of non-curative treatment. When reflecting on the challenges oncology nurses perceived in providing care in this setting, they frequently

noted that the high volume of patients, high acuity, long wait times and the mixed population / mixed care needs of patients seeking help at the emergency room make it challenging to provide the kind of care they expect for their patients.

I find that the emergency room is really unkind to palliative care patients. It's just that the whole environment is unkind. It's not that the people don't intend to be kind to another human being. It's just that they become low priority. They say "Well why can't cancer care do something about this in the morning?" (Participant 1)

Oncology nurses in this study commonly spoke of the judgments they perceive from other health care providers when patients living with advanced cancer present to the emergency room seeking help in times of crisis. Questions like "why can't this be managed in the cancer setting?" and "Why isn't this patient palliative?" and "Why hasn't DNR (do not resuscitate) orders been discussed?" are frequently encountered by oncology nurses when trying to facilitate care in the emergency room setting. Within these questions, oncology nurses perceive that there is a stigma placed on the oncology patient living with advanced cancer. In other words, they perceive that the patient living with advanced cancer is 'not worthy' of care in the emergency room and that emergency room staff are quick to make assumptions about the futility of further non-curative cancer treatment when the oncology patient presents to the emergency room in crisis.

Oh you can't come in and get stitches, you're a palliative patient! It almost feels to me sometimes that it is that bad, but I know it isn't. Yeah. (Participant 1)

Our patients are not treated appropriately when they go to the emergency department...they see them and they just immediately think that they should be palliative. And "why are we doing all this for this patient?" (Participant 3)

A lot of patients will not go to emergency unless they're death and dying... they get labelled as cancer patient and are in the leftover bin. So they think why bother? I'm seeing, I'm going to cancer care tomorrow. I can see them... People

voice that. That they feel that they are not as worthy as a healthy person coming through the doors. (Participant 7)

Other participants commented about how the limited disposition options in the emergency room, and particularly the option of transfer to a palliative care bed if the patient is labelled as 'palliative' serves to perpetuate the notion that all oncology patients are palliative.

With emergency...I think their motto is "everybody that has a cancer diagnosis has to be on the palliative care program so they can get them out of their department and in a palliative care bed as quickly as possible." (Participant 4)

Participant 4 went on to describe how this assumption carries over to patients for whom the intent of treatment is curative. In other words, assumptions about the futility of further treatment and assumptions that the patient ought to be palliative occur even in situations where the cancer may still be cured and the crisis is simply one related to the side-effects of treatment.

(When patients develop complications of curative intent treatment) their thing is "they should be on the palliative care program too", and I'm going "well we're going for complete remission here!!" You know, why should they be on the palliative care program? Well, because they have cancer. (Participant 4)

One participant challenged the notion that a patient is considered 'not worthy' when seeking help in the emergency room in times of crisis. She questioned if the issue is really one that the oncology patient is not treated any differently than any other patient that comes through the emergency room doors. That is to say, oncology patients are not identified as 'special' in the context of the competing needs of other patients within the emergency room.

I have a feeling emergency room probably shakes their head and says...
"(Oncology nurses / Patients) have to realize they're not the only people out there that need help" (Participant 8)

This participant went on to share a story about a patient who had received one of the ‘newer’ non-curative treatments and developed severe symptoms during the treatment requiring urgent care in the emergency room. Her story illustrates how treatments that are common and perhaps taken for granted within the oncology world can seem completely foreign and, as she describes, ridiculous to care providers who are not familiar with them.

So (the oncology physician) said “well, we're giving him a drug... a monoclonal antibody and it's based on a mouse protein” (laugh). The emergency room physician just looked at her and said "What the heck are you doing to these patients?" and I thought, you know what, it sounds totally ridiculous. We just gave somebody something that's based on a mouse protein and we're wondering why they're having a reaction! (Laugh). And I thought they're out there shaking their heads saying "I don't know what you're doing over there!" (Participant 8)

It seems that oncology nurses sometimes internalize these judgments and question where they ‘went wrong’ when the patient develops a crisis requiring urgent care. Some participants spoke of how they ‘second guess’ themselves when a patient receiving non-curative treatment requires urgent care in the emergency room.

If something like that happens I think "ok they were just in the clinic - what did I miss? Did I not ask the right questions? ...and how are we failing them?... Is it chemo related or is it disease related? If its chemo related I feel responsible. (Laugh) I'm kind of hard on myself...I take that so personally. (Participant 2)

One wonders if this sense of self judgment and previously described feelings of failure, or angst about whether or not patients were inadvertently misled about the intent of treatment come with ‘owning’ responsibility for a patient’s emotional and physical safety as the patient moves toward end of life.

Holes in the net: Constraints in time, space and privacy

Oncology nurses interviewed in this study described tensions that they experience in work environment of their cancer center that adds to the complexity of coordinating

advanced cancer care. On reflection, these tensions seem very similar to the constraints oncology nurses perceive in the emergency room setting. Participants frequently spoke about the pace of work and the volume in the number of patients that they provide care for as part of this reality. For example, participants spoke of the difficulty finding ‘space’ in treatment areas to provide supportive treatments and the angst they experience when having to coordinate care outside of the environment that the patient has become comfortable with.

If you can get treatment room space! I really feel bad for a palliative care patient whose known me for ten years and needs a transfusion and they are in their last months or weeks of life and our treatment room’s full...and I end up having to send them ...to a strange setting. (Participant 1)

Tensions about ‘space’ are also a concern in the clinic setting. It seems that the allocation of space for private patient assessments and discussion is limited to the days that the oncologist is scheduled to run a clinic. Participants described the distress they experience when this lack of private space necessitates nursing assessments and ongoing sensitive goals of care discussions to be conducted in spaces with little privacy or comfort for either the nurse or patient.

So I’m sitting there having a lady peel down her long-johns and stockings in a hallway to show me a leg ulcer today. Because there is NOWHERE. So you’re in a hallway, sort of in a window well, closing off as much as you can, being as discrete as you can, but that’s bad. There should be a private space to have conversations with patients even if it’s just a nursing function...(Sarcasm) so I’ve suggested phone booths all the way down the corridors, a two person phone booth so you can put the “cone of silence” around. Because to sit there in a corridor and shout “How about your bowels?” It’s not fair. But it happens over and over and over again. (Participant 1)

Within this quote, there is a clear sense of the moral distress that oncology nurses encounter when limitations in time, space, and privacy constrain their ability to adequately attend to their patient’s needs. In addition, the comment that ‘there should be

space to have conversations with patients even if it is *just a nursing function*' is intriguing. It seems that the organizational processes of how clinics are conducted and the allocation of space around physician time in clinic renders the nursing role in attending to holistic care less of a priority.

Further, it would appear that providing comprehensive supportive or palliative care within clinic time – i.e. attending to the physical, emotional, social and spiritual needs of patients living with advanced cancer when there is a physician present and the space for privacy – is problematic because of the numbers of patients that need to be seen and the small amount of time available to do so. This becomes particularly difficult when considering the amount of time that having difficult discussions about goals of care can take. Some participants spoke about how they would prefer not to have these lengthy discussions in clinic, even though this would be the only time that the physician would be available to participate in them and that they would be assured space for privacy, simply because of the time this would require and the struggles to manage this in the context of a busy clinic with many patients waiting to be seen.

I would never bring them in on a clinic day if I had forewarning. Never. I'd have it in the hall instead, but at least I'd have the time...In fact I hate it when the physician has to have that talk with the patient in clinic and I don't have time to go in and pick up the emotional pieces because I've got to go get the next person in a room. (Participant 1)

When there is little time allocated for attending to a patient or family's emotional needs, oncology nurses are tasked with 'picking up the emotional pieces' while rushed to 'keep up the flow' of a busy clinic.

When thinking about the personal sense of responsibility that oncology nurses have described in ensuring the emotional and physical safety of their patients, one can

appreciate the moral distress experienced in her own practice when constraints in time, space and privacy seem to inhibit the nurse's ability to attend to those needs in a way that is consistent with her personal philosophy of care. One wonders if this experience is part of the heightened vigilance that oncology nurses describe in going 'above and beyond' accepting personal sacrifice as part of her role and engaging in 'defensive nursing'. However, it would seem that this distress is amplified in situations where the oncology nurse is obligated to send the patient to a care setting outside of the ambulatory cancer setting 'safe zone' where there is less certainty or confidence that other nurses will make the same sacrifices or have the same level of vigilance in attending to the particular vulnerability of the patient and family living with advanced cancer.

Holes in the net: Falling through the cracks

Some participants shared intensely uncomfortable stories where patients were not prepared to stop non-curative treatment and the 'partial safety net' of pieced together services was inadequate to save the patient and family from 'falling through the cracks' in times of crisis. Participant 3 previously shared her experience with a young mother who had two school aged children and how she supported the patient's decision to "keep fighting" the disease in the hopes of buying more time with her children. She went on to describe how crisis later unfolded and the patient's "awful death".

I knew if he didn't bring her to the hospital, if she died at home, that the police would be there, they won't release the body for hours, because there'd be no letter of death, there'd be nothing because she wasn't palliative. And all I could think of was those two little boys with the police there, and their mom's body there and how traumatic that would be for them. So I said ok...you bring her and I will come to emergency and meet you there. So when I got there... she was already gone...I said "how are you doing" and he said "I think she's gone already"... "I think she died on the way here...I think she died in the car...she just looked like she... I couldn't see her breathing." (Participant 3)

This participant went on to describe another troubling crisis that a patient and family experienced when the patient who had made the decision to continue non-curative treatment died unexpectedly at home and a family member called '911'.

(When paramedics arrived) they started CPR on him. And she told me, she said "...They are pushing on his chest!! They are pushing on his chest!" And I said, "They have to. They have to do that". And I said "There's nothing you can do...Just let them do what they have to do, they'll bring him to the hospital".(Participant 3)

When reflecting about these two stories, the nurse went on to make the following observation:

Families, in the end, if they don't go palliative...that conversation usually doesn't take place about what to do when they die. Because if they're not ready to hear it, or they think that they're going to die in the hospital, and so sometimes that conversation doesn't take place. So when it does come and they are home then there is panic. (Participant 3)

This leads to wonder if incorporating discussions about advance care planning and talking about the "what if" scenarios while patients continue to receive non-curative treatment may have a role in planning for the possibility of death at home and averting some of the angst of crisis. In other words, could advanced care planning provide another 'safety net' to ensure support in times of crisis?

Participants in this study seemed to have varying thoughts about advanced care planning in the context of providing care to patients with advanced cancer. One participant described how she introduces advance care planning as part of the normal conversations had with every patient who walks through the doors of the outpatient cancer clinic. She observed that framing advanced care planning in this way helps to open up goals of care discussions in a way that is non-threatening. These discussions

may or may not segue into discussions about planning for end of life but at the very least, it provides an open invitation to re-visit the discussion when the patient is 'ready'.

Often when I'm talking to patients about prognosis I try to give them a sense of hope...I talk to them about health care directives and sometimes that may be the only conversation that I start off with...because sometimes they're not ready to talk to you yet about palliative care. But it's at least starting the conversation...I try to normalize it...like this is something we discuss with everybody that came through our doors. (Participant 6)

Other participants spoke about how in her experience, advanced care directives are rarely discussed unless the patient receiving non-curative treatment has made the decision to stop treatment. When reflecting on this, one participant marvelled that staff and patients seem to operate on the assumption that even though the patient is dying, they're not dying.

You know when I think about it, how stupid are we for not having that (resuscitation) status on their chart? But most of the time we don't. And we've had some really, really sick people... even the ones that...wanted to continue on treatment despite the fact that we felt that they were at a point where they should be palliative because the treatments weren't working, I don't believe on any of those patients that we had a DNR status on their charts. I think had any of the come into our clinic at any given time, had any of them died in the clinic, it would have been a phone call to (the oncologist)...with "what do you want us to do?" (Participant 3)

Although oncology nurses in this study often spoke of re-enforcing the non-curative intent of treatment with patients (using language consistent with the understanding of cancer as a chronic illness – i.e. that the treatment goal is control, not cure), it seems that open discussion about the terminal nature of the disease - and planning for end of life - may be delayed if the patient is perceived to be not 'ready' for the discussion, or more specifically, not ready to stop chemotherapy treatment. Discussions addressing preparations in the event that death happens at home are commonly held when a person makes the transition to coordinated palliative care

services. It seems that if that transition does not occur because of the ongoing treatment goals or expectations of the family, families may not have the information or the supports they need to draw upon in times of crisis.

Staying in Touch and Letting Go

In keeping with the conceptualization of palliative care as a ‘safety net’, participants have described feelings of trust in handing over care to palliative care nurses with the confidence that their patients will be ‘well loved and well cared for’. Having said this, many participants spoke of maintaining a sense of connection or ‘staying in touch’ when care has transitioned to the palliative care team. This seems to occur with greater frequency when the patient and family still require part of their supportive care through the outpatient clinic (for example, blood work, transfusions, IV hydration), or if the patient and family are perceived to need ongoing emotional support because they have established a close trusting relationship with the oncology nurse. Having said this, the experience of staying in touch may look different depending upon the role that the oncology nurse occupies within the clinic.

You start to pull away when people go palliative. The only reason that we would see patients once they are palliative is for hydration, um, port care, mostly hydration though... (It is different for the clinic nurse)...she deals a lot more with palliative care patients than we do in treatment... (Participant 3)

This is not to say that the oncology nurse loses interest in what happens to the patient who has stopped non-curative treatment, only that they may no longer be personally involved in providing care either in person or on the phone. In reality, participants often described how they would ‘check in’ with other staff when they thought about a particular patient and how they might be faring in the community.

I'm very quick to talk to the clinic nurses about their patients... I take an interest... I want to know what's happened to the patients. So I will ask...and then I will try and tell the treatment room staff as much as I can, you know? ...Because that's the only way we stay connected. (Participant 8)

The experience of “staying in touch” may also be different if the oncology nurse does not have full confidence that the other care team will manage the advanced cancer patient / family's care needs in a manner that is consistent with their personal philosophy of care. Participants in this study often described situations when they would make more of an effort to stay involved in the patient's care when it had transitioned to other care teams. This seems particularly strong when participants are not confident that the care team they are handing off to have the knowledge or skill or approach required to ensure that the patient receives the kind of palliative care they deserve. For example, one participant described situations where she would remain involved (making visits to the hospital or even calling the oncologist asking her to visit patient in hospital) when she had concerns that the patient's palliative care needs were not being met adequately. It would seem that ‘checking in’ in this context is ‘above and beyond’ expectations of the oncology nursing role.

It's just sometimes, on the ward, I do kind of watch a little bit. Maybe I shouldn't but I do. And then sometimes if I don't agree with something, I'll go to (the oncologist) and say you know, this and this is happening, can we get in there somehow again?... We'll get something done for the patient that we feel needs to be done. You know, because some GPs are not as good as others and as comfortable with palliative care as others. Participant 4)

Having said this, the motivation to stay in touch with other care teams was not always described as a lack of trust but rather that the sharing of information. Participants described how communication with the new care team may help to inform patient care or provide opportunities for mutual learning and growth.

It's nice to know that when (the patient dies) at least you hear they've passed comfortably or if there's any issues because you learn...sometimes from the things you could do better with your own care for the patients too. (Participant 5)

Participants also described situations where other members of the health care team 'stepped up' to provide the palliative knowledge and support care teams may need. One participant described how the palliative care clinical nurse specialist provides consultative support to ward staff, providing the required 'backup' and has transferred patients with complex needs to the palliative care inpatient unit when required.

Usually everything is fine if their symptoms are that difficult. (Palliative care Clinical Nurse Specialist) has been really good about getting them out and getting them a bed. If their symptoms are something that can be managed here, usually it's OK. But (Palliative care Clinical Nurse Specialist) gets them out pretty quick. (Participant 4)

In the above discussion, participants spoke of their own personal threshold in knowing when they ought to continue the relationship with advanced cancer patients no longer receiving non-curative treatment and the extent of that relationship. However, oncology nurses also spoke of the motivations patients and families living with advanced cancer may have in 'staying connected' to the ambulatory cancer clinic and oncology nursing staff.

Some patients want to still come because there's hope that maybe something will change or they'll get better or they just need that reassurance that "these people know me, they know what I've been through". (Participant 5)

I think they keep coming back because they like to be here too. They feel safe here ... they'll leave here feeling 100% better... and of course they think we're wonderful again! (Laughter) and then they come back. (Participant 3)

So even though (the patient) is not getting active treatment per se, they're still kind of living life a bit. It gets them out of the house, they get to see the people that they've come to know, there's kind of a little bit of normalcy in a world that is changing a lot for them. (Participant 5)

This notion of the cancer care experience becoming the ‘new normal’ in a patient’s life is an intriguing one. It seems that in the context of the relationship that is established throughout the continuum of advanced cancer– the sharing of the ‘ups and downs’, the hopes and disappointments – patients and families may find meaning and support in the cancer community they have grown comfortable with.

Although participants recognized the comfort that patients and families may take in maintaining a relationship with the ambulatory cancer clinic after the decision to stop non-curative treatment and the transition to palliative care services, they expressed feelings of uncertainty about the appropriateness of initiating those contacts themselves.

Sometimes it’s hard because you always think about the patients and sometimes you want to phone and see how they are but you never know if you should or not. ... Sometimes it’s hard to make that change. Sometimes it’s hard to let them go and not treat them. Sometimes we just want to keep treating them just so that they keep coming back. (Participant 3)

It all depends on what the patient wants too. Some of them just kind of, you know they’ve had their experience at cancer care so they move on to almost like the next phase for some of them...they’re at peace with what they’ve had done, so they just kind of are focused. (Participant 5)

It almost seems that in hesitating to make the connection oncology nurses consider: Am I making contact for the patient’s benefit or my own?

In times of uncertainty, participants often spoke of letting the patient make the ‘first move’. At times, there seems to be a particular awkwardness in situations where oncology nurses encountered either the patient or the family of the deceased in public places. Participant 3 shared her feelings of awkwardness when meeting the family of the young woman weeks after her ‘awful death’.

You know when you see somebody and it just...you go "Oh, I know you from somewhere" but you can't place it right away?... He turned around and saw me, and we both kind of went "oh, how are you?" and as soon as it came out of our

mouths, I think we both realized where we knew each other from. And I could almost see his face change, and I'm sure mine changed at the same time.
(Participant 3)

This inclination to allow patients or families to 'make the first move' may be reinforced by the awkwardness that participants described when describing situations where they had initiated contact enquiring about the patient only to learn from family that the patient had died.

You go "how's so and so' and you know "well he died last week" and you say "oh really" (laugh) you know, and then you really feel bad that you haven't checked up on them or something. You know, so that's happened a few times.
(Participant 4)

Loss in letting go: Finding Balance

Participants often described a sense of loss as their relationships changed with patients who were no longer receiving non-curative treatment whose care had transitioned to other teams. Within this experience, there too seems to lay inherent tensions. Oncology nurses in this study often recognized the need for these transitions given the reality that 'new' patients with advanced cancer are entering the clinic requiring their care and expertise. Some seemed to frame the changing relationship with their patients as a natural part of their role within the cancer continuum expressing confidence that the patients who are transitioning to palliative care are in 'good hands'.

But as long as they're looked after, it's ok. You know what, because somebody else is there that needs us... I don't really feel a sense of loss. I look at it as more of a, not a stepping stone, but just a different phase. Their life goes on, our life goes on. (Participant 8)

However, other participants, while acknowledging the need to 'move on' to care for the next person occupying the treatment chair, seemed to struggle with their personal sense of loss in the context of their changing relationship with the patient.

And we all know that we, every one of us feels that (loss) when one of our patients dies. (Silence, tears) And at the same time you know that despite the loss, you carry on. Because there's somebody else in that chair who needs you more now than that person who died. (Participant 3)

Within this experience, participants described a lack of emotional closure when limited in their ability to 'see the family through' death.

You develop a rapport with these people so it's kind of hard to just forget about them, even though you're not seeing them on a regular basis. (Participant 5)

I prefer the old days where we would do it all, you know? You just, you see it through, you see them at the beginning, during and at the end. Yeah. So It's hard (silence - tears)...I find that yeah, once they're in the palliative care program, I know even though we've seen them for like years, it's just like, it's almost finished. (Participant 2)

Participants sometimes spoke of how difficult, but also how meaningful it felt to witness the decline toward death for those patients that continued to maintain a connection to the clinic throughout the final stages of their illness.

And those ones are harder because you follow the process with them...every time you seen them they're a little bit smaller than the last time and a little bit weaker...and then they eventually stop coming quite as often... (But)I really enjoy those ones who keep coming back to see us because somehow I feel like even though we can't treat them, we can still help them. There is still something we can do for them (Tears). So I like that. (Participant 3)

The quote above supports earlier discussions about how oncology nurses may internalize the inability to control the disease as a sense of failure. In this context, the ability to continue providing supportive 'palliative' treatments seems to provide oncology nurses with the comfort that they can continue to 'do something' to help the person as they reach end of life.

However, it would seem that shifting between patients who are receiving palliative or strictly supportive care treatments and patients receiving disease focused

treatment is complicated within the outpatient cancer setting. In witnessing the decline toward death, participants sometimes spoke of the need to ‘stay strong’ for both colleagues and patients in the treatment area when ‘switching gears’ between providing care to patients who are still hoping for a cure or continued control of their disease and patients who are reaching end of life.

And then when we switch gears, that now our intent is completely different for this person, so in this chair...we’ve got all the chemo out, we’re treating a cancer, we’re going for control and in this chair he’s at the end of life, we’re just going for comfort measures... and you kind of go between them. (Participant 4)

As a nurse, you learn how to give bad news or sit with somebody who is dying and then walk out the door and put your smile on for everybody else that’s there who needs that smile (tears). Even though you don’t feel like doing it, and you don’t want to do it, but you have to. So in some ways, it’s a really tough job to do. But I have never felt so blessed in my career to be able to do this. (Participant 3)

It would seem that within the care environment, oncology nurses are required to be ‘different nurses to different people’ depending on their patient’s treatment goals and stage of their illness.

Despite the challenges that oncology nurses describe in navigating their relationships with patients and families as they transition toward end of life, these relationships reaffirm the oncology nurses’ sense of meaning and purpose in her role. Participants commonly described how the relationships they established with patients and families living with advanced cancer were personally transformative. That is to say that oncology nurses frequently observed that their patients are always teaching; teaching those around them to believe in miracles, to believe in the resiliency of the human spirit, to focus to the truly important things in life (love, relationships, friendship) and to appreciate life in its fullest sense.

However, it also seems that context of the work environment, and the need to stay strong for other patients who need you in the moment, can force the grief oncology nurses experience into the background to be reconciled in a moment of privacy. Several participants spoke about how moments sometimes arise with colleagues to share this grief together.

Well crying is good. (Laughter) I work with a bunch of criers. And in back when one starts, we all start. So that's a good thing. And you know at the end of the day you've done your job. It's just in that moment...it's a release of all your emotions and you usually feel better after. (Participant 5)

Traditional means of closure (i.e. attending funerals or memorial services) are not often feasible given the number of patients that oncology nurses care for. One participant spoke about being cautious about relying on funerals to grieve.

I know some of the girls that just started, they got to be really close with some of (the patients) and they wanted to go to the funerals. I'm going "you can go, you know, you're allowed compassionate leave, but are you going to go for all of them?" You know, just be careful. (Participant 4)

Other participants spoke about participating in grief work activities within their workplace as an opportunity to let go of the grief experienced as patients die of advanced cancer.

We've had three of them, for just the nurses and the clerks. And we go into the chapel and they light a candle and we say a prayer. And it is really hard to get through. And then, she reads all the names of the people that we've lost over that time period, and then usually there's something that we do that's uplifting...And we all have a nice cry and that helps...all of us are kind of like "do we have to do that again?"...And then we all feel like 200% better when we do it. (Participant 3)

While this quote reveals the reluctance among oncology nurses to 'open up' the cumulative grief that is experienced on the job, it also speaks to the benefit of setting aside dedicated time for team 'self care' to let go of the grief that is carried. It also

suggests that oncology nurses find comfort in the shared experience of loss in the safe environment of colleagues who understand the complexity of their lived experience.

In summary, the oncology nurses' experience of providing non-curative treatment in an outpatient setting is extremely complex and multifaceted. Overlapping tensions inherent in the various understandings of advanced cancer and palliative care, and the context of existing services shape the context of the delicate balancing act that oncology nurses perform when balancing hope and miracles with honesty and witnessed suffering. Oncology nurses play a pivotal role in navigating these tensions with the patients and families for whom they are providing care by revisiting treatment decisions and goals of care throughout the trajectory of the illness. The foundation of this experience is forged within the nurse-patient relationship and satisfaction within this role seems closely linked to the oncology nurse's ability to attend to the emotional and physical safety of the patients and families in her care.

Chapter 5

Discussion

As mentioned in previous chapters, the interpretations derived through phenomenological inquiry reveal the hidden complexity of lived experience – they present different possibilities or ways of thinking about a phenomenon that otherwise might be taken for granted or coloured by unexplored assumptions. This study reveals the many intriguing and at times conflicting tensions inherent in oncology nurses work as they provide non-curative treatment to patients and families living with advanced cancer in the outpatient cancer setting. The following discussion is not presented as a definitive work describing this experience, but rather as an invitation to ongoing discussion within the palliative, oncology and general health care community to engage in dialogue about how the idealized philosophy of integrated palliative / cancer care might be supported in practice.

The following work will explore how the themes generated in this inquiry relate or add to previous understandings about how non-curative cancer care is experienced in oncology nurses' practice including:

1. Palliative care in oncology nursing practice: A discussion about how palliative care is understood and enacted in daily oncology nursing practice.
2. Goals of Care Discussions: A discussion about the oncology nurses role in goals of care discussions and other understandings that may contribute to how this role might be understood.
3. Anticipating Crisis: A discussion about the phenomenon of witnessed suffering and exploration of the possibilities in building a 'durable safety net'.

4. Cumulative loss and the emotional burden of witnessed suffering: An exploration of the oncology nurse-patient relationship and finding sustenance through loss.

Palliative Care in Oncology Nursing Practice

When reflecting upon the various conceptualizations that participants used to describe their personal understandings of cancer and palliative care, it would seem that meaning of palliative care in practice bears further discussion. Despite the evolving conceptualization of palliative care as holistic patient and family centered care that attends to the physical, emotional, social and spiritual dimensions of the cancer illness throughout the illness continuum, current literature suggests ‘palliative care’ continues to be strongly equated with end of life (Paice, Ferrell, Coyle, Coyne, & Callaway, 2008) or described as care for people who have ‘failed’ efforts to control the disease (Sesterhenn, Folz, Bieker, Teymoortash, & Werner, 2008).

Two studies in particular have explored the meaning and understanding of ‘palliative care’ with oncology nurses working in the United States. Pavlish & Ceronsky (2007) conducted focus groups with 33 oncology nurses working in one of three inpatient care settings. They found that while many participants described palliative care as a process that shifts the focus of care to managing symptoms and working toward holistic comfort and quality of life, there was confusion about when or how to include palliative care specialists or coordinated palliative care services in the care of patients (p. 796). Similarly, Mahon & McAuley (2010) mused that “oncology nurses who had very inclusive and supportive approaches to their everyday practice of nursing – approaches that included most of the elements of palliative care – tended to provide very basic descriptions of palliative care” (p. E144). Participants of that study commonly equated

palliative care with hospice care (coordinated palliative care services). The referral to palliative care services provided the opportunity for oncology teams to ‘do something’ for patients who were no longer receiving disease focused treatment, even though another team - namely palliative care teams - would be providing care (p. E147). This was in keeping with Dudgeon et al. (2008) study that described how the involvement of palliative care specialists was not understood as a means of building capacity within the oncology team to provide palliative care but rather as a new primary team that would assume responsibility for the patient’s care (cited in Mahon & McAuley (2010), p. E147).

The findings of these studies seem to be in keeping with the language used by oncology nurses within this inquiry. Although participants derived meaning in their role from the strong relationships they established with patients and families while attending to the emotional and physical challenges faced when living with advanced cancer, this was not explicitly described as palliative care. It seems that within the outpatient cancer clinic, where advanced cancer has become a chronic illness that can be controlled for a time with treatment, the patient ‘becomes palliative’ when care either transitions or becomes shared with care teams providing coordinated palliative care services. The process of ‘becoming palliative’ is described as a process that evolves over time as the nurse ‘tests the waters’ with patients exploring the balance between the intent of treatment and quality of life. The decision to ‘become palliative’ is made when the burden of illness and treatment grow to outweigh the benefit and the patient makes a decision to stop further disease focused therapy and enrol in coordinated palliative care community supports.

Many writings seem to suggest that further education about palliative care is required for oncology nurses and professionals throughout the entire health care system to galvanize the ‘culture change’ that is required to fully integrate palliative care within cancer care (Mahon & McAuley, 2010; p. E147). While palliative care focused education likely plays an important part of supporting oncology nursing practice, and indeed, participants within this study expressed frustration about their lack of knowledge about how to engage palliative care services and an interest in further education, my study suggests that oncology nurses work hard to provide holistic care in keeping with described palliative care philosophies. However it seems that the context of care, and tensions inherent within the experience of providing palliative focused care to patients receiving non-curative treatment complicates the fulfillment of this ‘culture change’.

Oncology nurses described how constraints of time, space and privacy and the competing demands of juggling the complex physical, emotional and practical needs of patients requiring care can interfere with holistic care they aspire to provide. These constraints have particular significance when thinking about the time and privacy required when having sensitive discussions about quality of life and goals of care. Participants described mixed success in attending to a patient’s comprehensive care needs in the context of a busy treatment room where patients are waiting for treatment or in a busy clinic where the nurse simultaneously juggles conducting nursing assessments, placing patients in rooms to keep the clinic flowing and ‘picking up the emotional pieces’ after difficult discussions. This is in keeping with other studies that have explored the challenges of integrating ‘supportive care’ philosophies within the cancer treatment setting. In a study conducted by Mcilpatrick, Sullivan & McKenna (2006) exploring

outpatient oncology nurses' experience providing outpatient treatment, high patient volumes and competing tasks when performing care were found to constrain oncology nurses ability to administer the holistic care they aspired to provide. The result was that oncology nurses were tasked with 'nursing the clinic' rather than 'nursing the patient' (p. 1175). Along a similar vein, historical organizational processes and more specifically, the balance of power and dominance of physicians in deciding when to include supportive care, the growing numbers of patients being treated without growth in resources (time and space) to care for them, and the cultural dominance of the 'treatment imperative' within the cancer setting was found by Willard and Luker (2005) to render 'supportive care' as subordinate in the context of a busy clinic. In their words, "Supportive care was often seen as an optional extra – to be offered within the constraints of the treatment agenda, if and when time allowed" (Willard & Lucker, 2005, p. 331).

This resonates strongly with earlier discussions about the organizational processes that allocate space around physician time and limit opportunities for oncology nurses to assess their patients or engage patients in sensitive goals of care discussion in a setting that attends to their physical and emotional vulnerability. It also resonates with how some oncology nurses described their role in administering treatment. The role of the treatment nurse was described to be primarily task focused (i.e. the safe administration of treatment) and 'nursing the patient' was described to be more of the clinic nurses' responsibility. Constraints of time and the number of patients waiting to be treated featured prominently within that discourse.

It would also seem that the structuring of palliative care services is a large contributor to the commonly held conceptions that palliative care ought only to be given

at end-of-life when treatments have failed. Oncology nurses commonly spoke about the appropriateness of facilitating patient connections with palliative care providers early in the course of illness. Further, oncology nurses trust that palliative care providers share a philosophy of care that both acknowledges and pays special attention to the physical, emotional and social vulnerabilities of patients and families living with advanced cancer. However, access to coordinated care services is constrained by patient and family decisions to pursue ongoing disease focused treatment. As a result, oncology nurses must construct a network of ‘patchwork’ supports to protect the vulnerability of patients and families who are struggling with the growing burden of advanced cancer and its treatment in the community. As with nurses in Pavlish & Ceronsky’s study (2007), oncology nurses expressed their frustration about being caught between services when trying to coordinate care. Participants frequently expressed their personal sense of injustice that patients who are seeking treatment in the hopes of controlling the disease or ‘buying time’ are excluded from services offered through coordinated palliative care programs. This sense of injustice seems amplified by the inconsistencies that exist between the urban health region and surrounding rural health regions that allow concurrent chemotherapy treatment and palliative care services.

It is perhaps not surprising that philosophical notions of palliative care throughout the cancer illness continuum are not realized in light of the fact that coordinated palliative care services are rationed to the final months of life. It is well recognized that the limited funding of existing palliative care programs across Canada has contributed to this dichotomy and forms part of the argument to lobby for a national initiative to provide palliative care more consistently and inclusively across the country (Carstairs, 2010).

Having said this, it is curious to consider what seems to be missing when oncology nurses ‘patch together’ services to make this connection to palliative care early in the course of a patient’s illness.

As discussed earlier, participants in this study frequently spoke of ‘working the system’ to add palliative care community nurses while the patient continued to receive non-curative treatment. This provides much of the same type and amount of service as would be available if enrolled to the coordinated palliative care program. The primary difference being patients enrolled in the palliative care program have the option of contacting their palliative care coordinator to facilitate direct admission to a dedicated inpatient palliative care unit when symptoms become overwhelming to manage in the community. When patients who are not enrolled to the palliative care program develop complications requiring urgent care, participants described how patients usually turn to their oncology nurse for help as their first option. If the oncology nurse is unable to manage the care needs in the outpatient setting and unable to coordinate a direct admission to hospital or direct admission to a dedicated palliative care unit through ‘urgent enrolment’ to palliative care, the patient is sent to the emergency room for care. It would seem that the greatest angst that both oncology nurses and arguably patients and families experience when they have not transitioned to palliative care services seems to occur when the burden of illness or complications of treatment become suddenly overwhelming to manage in the community. This will be explored in greater detail in future sections of this chapter, however, it leads to wonder if there is a role for developing dedicated inpatient supports that support a blended oncology / palliative care approach for oncology patients who experience crisis in the community.

Goals of Care Discussions

Oncology nurses in this study describe having a prominent role in ongoing discussions evaluating goals of care with patients receiving non-curative treatment. Participants frequently described how they would ‘test the water’ with patients and families with each visit to the clinic to gauge patient perceptions about the value of continuing treatment as a means of assessing ‘readiness’ to discuss the alternatives. If oncology nurses perceive cues from the patient or their family that the burden of treatment is becoming harder to manage, or an interest in discussing alternatives, they will readily take that opportunity to re-evaluate goals of care. Having said this, there are several tensions within this experience that bear further discussion.

Many participants spoke of the approach used by the oncologist that they work most closely with when speaking about their personal approach to frame discussions about goals of care with families. This seems to be in keeping with other studies that have explored the meaning of palliative care with oncology nurses. Mahon & McAuley (2010) found that oncology nurses held to the idea that decisions about palliative care ought to be made by patients (or their designate decision maker) or the physician. In their words, “The role of the staff nurse was not seen by any respondent as primary; however, several respondents believed that staff nurses had an important but secondary and sometimes covert and indirect role in decision making” (p. E146). Although most participants in this study identified that they have a key role in the ongoing discussions about goals of care throughout their relationship with a patient and family, the approach described in having those discussions seemed to depend on the context of the situation

(i.e. perceived readiness of the patient), the context of their relationship with the oncologist, and their perceived role within the clinic. Some participants described situations where they would have direct involvement in these discussions, for example discussing goals of care, quality of life and the impact of treatment as part of the oncologist / patient visit within the clinic, while others described situations where a 'softer approach' was used. In these situations participants described 'raising the alternatives' in a way that would not 'overstep bounds' in the hopes that empowering patients with information about their disease and alternative treatment options families might be empowered to discuss those alternatives with the oncologist.

It would seem that the oncology nurses' perceived role within the care team in having these discussions and the approach used by the oncologist when discussing the non-curative nature of the illness at diagnosis sets the tone for how these discussions are carried through the course of non-curative treatment. Several participants described avoidance of 'palliative' language within the clinic prompting the use of 'chronic' or 'control' language when discussing the intent of treatment. Ambiguity about the degree of candour used when discussing prognosis or the extent to which the patient and family absorbed this information frequently prompted a 'softer approach' when gauging readiness to discuss stopping disease focused treatment. This raises interesting questions when considering the research about the disclosure of prognosis in oncologist-patient discussions at diagnosis, and patient and family expectations of treatment.

Although the various forms of cancer behave differently early in the disease, the path toward death is usually marked by progressive functional decline in the last year of life and marked decline in the months preceding death (Finlay & Casarett, 2009; Lunney,

Lynn, Foley, Lipson & Guralnik, 2003). Despite this 'predictable trajectory', clinician estimates of prognosis tend to be inaccurate and are frequently overoptimistic (Christakis & Lamont, 2000; Glare, et al., 2003). Further, the longer the physician relationship, the less likely the physician will predict prognosis with accuracy (Christakis & Lamont, 2000) suggesting that perhaps having an established relationship makes it more difficult to recognize or acknowledge end of life. Participants in this study described particular difficulty witnessing the transition to end of life with patients that they have cared for through years of non-curative intent treatment. One wonders if the length and depth of relationship with patients and families adds a layer of complexity to defining when a patient has reached end of life for oncology nursing staff as it seems to with their physician colleagues.

In addition to the challenges in estimating prognosis, many studies suggest that physicians are reluctant to discuss prognosis with their patients. Daugherty & Hlubocky (2008) surveyed 729 oncologists in the United States about their approach to disclosing prognosis and found that while 98% of physicians would disclose the terminal nature of the illness, fewer would provide information about prognosis (p. 5989). Of oncologists surveyed, 42% routinely discuss prognosis, 33% ask patient if they want to know and disclose if the answer is yes, and 16% talk about prognosis only if asked directly (p. 5990). In a prospective study of 98 consecutive cancer patients meeting with their oncologist to discuss the role of non-curative treatment versus 'watchful waiting' in the Netherlands, 84% of patients were told about the non-curative nature of the illness but only 53% were told about the expected course of their illness and 39% were given information about prognosis (Koedoot, Oort, de Haan, Bakker, de Graeff, & de Haes,

2004). In general, physicians are more likely to disclose their inability to cure the disease rather than provide specific information about disease progression and prognosis (Finlay & Casarett, 2009, p. 255). Further, studies suggest that even when prognosis is explicitly discussed, families may have different understanding about the intent of treatment or that they will not be cured of their disease (Chow, et al., 2001; Craft, Burns, Smith, & Broom, 2005; Van Keffens, Van Baarsen, Hoekman, & Van Leeuwen., 2004).

Within this study, participants spoke of feeling comfortable with ‘testing the water’ as part of their routine assessments when helping the patient and family to manage the side effects of non-curative treatment and its impact on quality of life. Many described how they actively look for that opportunity to talk about the alternative of stopping treatment, particularly as it becomes clear that the patient and family are struggling with the cumulative burden of the illness and treatment. However, oncology nurses are often uncertain about what treatments might be considered ‘down the road’ if the current treatment ‘fails’, how long a patient may have to live (particularly in the context of past witnessed miracles) and are cautious about over-stepping the boundaries of their role. As a result, oncology nurses look to the support of the oncologist to initiate discussion about treatment alternatives.

There is an interesting dynamic within this phenomenon. On the one hand, oncology nurses do not perceive that they are in a position to make decisions about the course of treatments - this is negotiated between the oncologist and the patient and family – however, oncology nurses are witness to the mounting burden of treatment that patients, families, and oncologists seem slow to acknowledge and describe having a key role in raising the question of quality of life for both patients and oncologists to consider

when making those decisions. Despite the importance of this role, oncology nurses in this study described a tendency to default to a ‘who am I to say?’ position of neutrality when presenting options and at times, a ‘covert’ role in providing patients with the information they need to discuss it with the oncologist, rather than claiming their role in decision making as part of the team.

The discourse of hope and miracles features prominently in the decision to maintain a neutral stance when presenting treatment options. The language of hope and the ‘fight’ to control the disease was frequently described as a motivation that patients have to continue with non-curative treatment, even in cases where it was clear that the treatment was no longer effective in controlling the illness. Discussions about stopping treatment are inherently fraught with concerns about taking away a patient’s hope. This is commonly described in the literature as a concern for health care providers (Andrew & Whyte, 2004; Daugherty & Steensma, 2002; Kodish & Post, 1995; Nekolaichuk & Bruera, 1998).

However, research suggests that patients may maintain a hope for cure while acknowledging the terminal nature of their disease (Clayton, Butow, Arnold & Tattersall, 2005; Finlay & Casarett, 2009). Further, Zimmerman and Rodin (2004) assert that this experience of having one foot firmly planted in both worlds is not a ‘denial’ of death, but a reflection of societal notions that have been shaped by advances in medical science (p. 125). There are also numerous studies that suggest the possibility of fostering hope while discussing prognosis and exploring goals that are appropriate to the patient’s level of function and stage of the disease (Back, Arnold, & Quill, 2003; Clayton, Butow, Arnold & Tattersall, 2005; Mack, Wolfe, Cook, Grier, Cleary & Weeks, 2007).

It would seem that for participants in this study, the experience of providing care to patients who continue to ‘fight’ in the hope of a miracle, and having witnessed past miracles with other patients, prompts oncology nurses to check their assumptions about the futility of treatment and respect the hopes of the patient, even in the context of witnessed suffering. In witnessing these miracles, oncology nurses default to a non-judgmental ‘who am I to say’ position and take care to remain neutral when presenting options. These notions are consistent with liberalist understandings of patient autonomy that value the patient’s fundamental right to self determination in choosing treatment (Badger & Ladd, 2009, p. 122). Assumptions about the appropriateness of maintaining a neutral stance so as not to bias decision making are observed elsewhere in nursing literature. For example, Andrew & Whyte (2004) refer to research findings that indicate patients living with advanced cancer are more likely to accept a lower chance of benefit and higher burden of treatment than compared to people without cancer – including their health care providers – to assert “health care professionals therefore need to be aware of their own attitudes and bias so that they do not allow these to influence the patient” (p. 112).

However, others have argued that presenting treatment options as though they are a buffet of choices without weighing in on decision making and framing these choices in the context of a patient’s particular health circumstances serves to ‘collude’ in this hopefulness (Helft, 2005). That is to say, that without knowledge of the likelihood of success of treatment in the context of their particular circumstances, patients will choose treatment with optimistic expectations that may be unrealistic (Harrington & Smith, 2009, p. 2669). Further, Earle et al., (2008) assert that the anecdotal experience of

miracles and patient expectations to ‘keep fighting’ are an insufficient argument to rationalize the offering of treatment that health care providers themselves would question taking. They argue that health care providers are obligated to utilize the knowledge and skills of their discipline to guide patients and families in their decision making (p. 3862).

Others have also challenged the dominance of notions of patient autonomy and self-determination in the process of decision making between patients and care providers. In his thought provoking critique, Lowey (2005) questions the assumption that patients and families could ever be fully equipped to make independent choices without the guidance and recommendation of health care providers. He argues that libertarian ideas of autonomy are fundamentally flawed as ‘freedom to choose’ is naturally constrained by the context of a person’s circumstances (p. 449). He further argues that it is unrealistic to expect patients and families to ‘choose freely’ when there is a clear imbalance in the knowledge and power required to inform and enact decisions (p. 450). He asserts:

A well-trained physician who has kept up adequately should not only tell patients whether their goal is achievable, but also must discuss the several options of treatment (or non-treatment) available and the possible side effects of each. Following such a discussion, the physician should, in my view, advise patients what form of therapy (including no therapy) they would prefer to use and why. Failure to do so and insisting that the patient decides what he wants done from a menu is “abandoning patients to their autonomy”. The patient – who is a moral agent – may decline the form of therapy suggested by their physician, but the physician – who likewise is a moral agent – is entirely within his rights to refuse the use of a therapy the physician feels to be inferior (p. 448).

These alternative understandings of hope and the role of health care providers in weighing in on decisions challenge the practice of maintaining a ‘neutral stance’ in the decision making process. It suggests that the information that is given to patients and families making difficult decisions to start, continue or stop non-curative treatment needs to be personalized and framed within the context of the patient’s particular circumstances and personal goals of care. The nature of the close nurse-patient relationship and the frequency with which oncology nurses monitor patients receiving non-curative treatment positions the oncology nurse as an important player in these discussions. There is opportunity for oncology nurses to assist families in thinking about what ‘quality of life’ means. Participants described that these discussions occur regularly within the nurse – patient relationship through the course of treatment. Perhaps the piece that is missing is the opportunity to raise concerns about witnessed suffering in the presence of both the patient and the oncologist and raise quality of life as the central focus of decision making discussions. Becoming visible in this process may help to ensure that quality of life is the central issue that is addressed in visits with the oncologist rather than narrow conversations about what might be the next line of treatment.

Having said this, and given previous discussions about how the approach taken by the oncologist sets the tone for these discussions, ‘weighing in’ on decision making may feel uncomfortable if the rest of the oncology team is not on the ‘same page’ about the appropriateness of this action. Perhaps open dialogue within the oncology team to ensure common understanding of a patient’s prognosis and what may be expected as the disease progresses would provide opportunity to agree upon how this information might be

presented to patients and their families so that a consistent message is given, and roles of each member of the care team are clear.

There have been several studies exploring the use of decision aides to facilitate open communication and assist with difficult decision making (Leighl, Butow & Tattersall, 2004). These aids have the potential to make the communication about prognosis, what might be expected as disease progresses, and the range of treatment options more explicit within treatment consultations (P. 1761). Brown, Burtow, Dunn & Tattersall (2001) conducted a randomized control trial where half of the patients enrolled received standard care, 25% received a question prompt sheet that was not specifically addressed within the consultation with the oncologist, and 25 % received a prompt sheet and the oncologist made a point of assuring patients of the importance of their questions and promised to answer them to the best of their ability. This study found patients who received a prompt sheet asked more questions about prognosis and the oncologist gave significantly more prognostic information. Further, having questions actively addressed by the physician helped to decrease anxiety, shorten the time of consultation and improve patient recall of the information (p. 1278). Similarly, Glynne-Jones et al., (2006) and Bruera, Sweeney & Willey (2003) reported overall patient satisfaction with using prompt sheets to assist with asking questions during their consultation with the oncologist. Given previous discussions about the inconsistent use of the word 'palliative' and tendency to avoid conversations about prognosis, the use of question prompts may legitimize these questions for patients and families who may hesitate to ask and build a culture where talking about treatment in the context of quality of life is part of routine care.

Anticipating Crisis

Oncology nurses in this study frequently expressed feelings of distress when their patients experience mounting burdens of progressive cancer and its treatment. Advances in cancer treatment have extended the treatment options available and the opportunity to continue the pursuit for control of the disease with second, third, fourth, and fifth line treatments. The cumulative impact of this prolonged non-curative treatment path can result in cumulative toxicity and increasing complexity in the acuity of patients treated in the ambulatory care setting. This mounting ‘fragility’ of the cancer patient over the course of time with treatment makes the personal sense of responsibility described by participants to protect the patient from harm all the more powerful. As discussed earlier, these tensions lead the oncology nurse to continually ‘test the water’ to gauge the timing of transition to establish a palliative ‘safety net’ of support services while balancing the competing desires to maintain hope (or emotional safety) with ensuring that the patient does not run into crisis with treatment (physical safety).

Within this experience, connection to palliative care services was often described as a reliable way of reducing the vulnerability of patients who are living in the community, outside of the clinic ‘safe zone’. Palliative care providers are trusted to care for fragile oncology patients because oncology nurses are confident that their patients will be ‘loved’ and ‘well cared for’ in a manner that is consistent with their personal, yet shared, philosophy of care. However, as mentioned previously, access to coordinated care services is constrained by patient and family decisions to pursue ongoing disease focused treatment. As a result, oncology nurses must construct a network of ‘patchwork’ supports to protect the vulnerability of patients and families who decide to continue with

disease-focused treatment but are struggling with the growing burden of advanced cancer and its treatment in the community. Oncology nurses in this study described feelings of moral distress and an internal sense of responsibility and personal failure when this ‘patchwork’ collection of supports failed to prevent a patient and family from falling through the cracks of the health care system. In particular, oncology nurses were distressed by the reception their patients receive when seeking care through the emergency department.

Concerns that oncology nurses have shared about the questionable appropriateness of the ER setting to manage the complex physical and emotional needs of patients and families living with advanced cancer are reflected elsewhere in the literature. It is widely recognized that the lengthy wait times and uncomfortable environment of the emergency room are a significant burden to families who present to the ER in a state of physical and emotional crisis (Barbera, Taylor & Dudgeon, 2010). In fact, emergency room visits have been used a quality indicator for poor quality care of patients living with advanced cancer at end-of-life (Barbera, Paszat & Chartier, 2006; Earle, Park, Lai, Weeks, Ayanian, & Block, 2003).

Barbera, Taylor & Dudgeon (2010) conducted a descriptive, retrospective study using administrative sources of health care data to determine the frequency and reasons that patients and families in Ontario present to the emergency rooms in the last 6 months and final two weeks of life. Of the 91,561 patients who died of cancer and were included in the cohort, 83.6% presented to the emergency room for urgent care at least once within the last six months of life. Of those, 63.5% made more than one visit with some as many as six or more visits (p. 564). Of the visits made in the last two weeks of life, 71.9%

resulted in admission, 20.7% were discharged home and 4.8% either died within the ER or en route to the ER (p. 655). The most common reasons that prompted patients with advanced cancer to seek urgent care were largely due to symptom burden (abdominal pain, dyspnea, pneumonia, malaise and fatigue, pleural effusions) and ‘failure to cope’ at home (p. 566). The authors suggest that these symptoms and concerns commonly fall within the domain of palliative care expertise and practice and speculate that those who are dying of advanced cancer might avoid disruptive and traumatizing trips to the emergency room if they had the quantity and quality of supports to address their needs and those of their caregivers (p. 566). This study is important because it suggests that a significant number of patients living with cancer develop concerns in the last 6 months of life that are unable to be supported at home. It is difficult to draw any conclusions about how supports ought to be provided or whether or not access to coordinated palliative care services reduces emergency room usage, however these findings highlight the importance of re-evaluating current practice with a view of providing meaningful support patients and family caregivers living with advanced cancer.

Authors of the above study suggest that preparing patients and families for what may be expected as the disease progresses may help in framing how these complications may be managed outside of the emergency room environment (Barbera, Taylor & Dudgeon, 2010, p. 566). Review articles, such as the one published by Nauck & Alt-Epping (2008), and indeed, the palliative approach that I have personally witnessed in clinical practice, suggests that the identification of these symptoms as an ‘emergency’ or an anticipated ‘crisis’ depends on one’s perspective. Within the cancer community and arguably the greater health care community, the term ‘emergency’ defines “an unforeseen

or sudden occurrence of danger that demands immediate action” (Nauck & Alt-Epping, 2008, p. 1086). However, one could argue that the symptoms that are likely to be experienced in the final months and weeks of living with an advanced malignancy can be anticipated in advance. As mentioned previously, the trajectory of decline within the final months of life when living with advanced cancer follows a fairly predictable decline followed by a dramatic changes – that could be called ‘crisis’ - in the final weeks of life. Typically these symptoms are a result of a combination of the overall burden of illness (fatigue, weakness, functional decline, metabolic disturbances) and symptoms specific to the malignancy (pain, dyspnea, confusion, etc) (Nauck, Alt-Epping, 2008, p. 1087-1090). Preparing patients and families for what might be expected as the disease progresses and having candid discussions about goals of care and the approach that ought to be used to manage them is part of the comprehensive focus of palliative care. However, this is a shift in thinking from traditional medical approaches of considering ‘what can be done’ in such circumstances to also considering ‘what ought to be done’ in light of the patient’s current circumstances and goals of care (Nauck & Alt-Epping, 2008, p. 1086).

Advance care planning, and talking about the ‘what if’ scenarios in anticipation of these the symptoms and care needs that are likely to develop with progression of advanced cancer illness forms a key component of planning for end of life. However, research suggests that advance care planning is rarely discussed within in oncology practice (Bradley et al., 2006; Levin et al., 2008). A Canadian study conducted by Bradley et al. (2006) reported that only 6.2% of the 209 patients receiving palliative intent radiotherapy during the study period (13 people) had documented discussions about CPR (p. 49). Although oncology nurses in this study commonly discuss quality of

life in the context of their patient's tolerance of treatment, few reported involvement in discussions about advanced care planning. Most frequently participants described discussing advanced care planning only when the patient receiving non-curative treatment made the decision to stop treatment. In fact, one participant marvelled that for as long as non-curative treatment is provided, staff and patients seem to operate on the assumption that even though the patient is terminal, they're not dying. This has particular significance when you consider the hesitation described by oncology nurses to enter into end of life planning discussions if perceived that the patient 'is not ready' and the sudden decline that often precipitates crisis goals of care discussions and the need for urgent care. Further, if the decision to stop chemotherapy is not made, anticipatory planning for a death at home is not discussed. The poignant stories shared by one participant about the traumatic and distressing deaths two of her patients (and their families) experienced in the community are testament to the importance of this kind of planning.

It would seem that oncology nurses typically have little preparation for entering into discussions about detailed planning for crisis in the community as this has generally fallen within the domain of palliative care nursing practice when a patient's care expands to include coordinated palliative care services. The one participant who described routinely discussing advanced care planning with patients in her practice has extensive past clinical experience in both the home care and palliative care setting. She described how these skills were acquired through experience, attending educational opportunities about communication and end of life, and witnessing communication styles role modelled in practice. This suggests the importance of collaboration and networking between the oncology and palliative care specialties and perhaps the value of integrating the role of a

palliative care advanced practice nurse within the outpatient cancer setting to support staff in building these skills. A recent study conducted by Prince-Paul, Burant, Saltzman, Teston & Matthews (2010) evaluating the impact of integrating an advanced practice palliative care nurse within a community oncology center found that the involvement of the advanced practice nurse in patient care resulted in a significant lower mortality rate and an 84% decrease in the odds of being hospitalized (p. 21). Along a similar vein, a randomized control trial conducted by Bakitas et al. (2009) exploring the impact of a nurse-led palliative care intervention found that patients and families who received ongoing information and support about symptom management, goals of care and decision making experience improved perceptions of quality of life (p. 747). It would seem that nurse-led interventions that provide patients with the information and supports about symptom management and planning for the future can improve the care of patients and families living with advanced cancer.

Finally, I believe it is important to discuss some of the specific concerns that oncology nurses in this inquiry raised about the perceived stigma that their patients encounter when seeking urgent care in emergency rooms. Participant accounts of the inadequate or inappropriate care their patients received in the emergency room or the judgements that seem to imply patients living with advanced cancer are less worthy of care are troubling. Oncology nurses in this study described powerful stories of patients being sent home in taxis with care needs that would have been best met with admission; stories of patients refusing to go to the ER and waiting until they could be seen in the cancer clinic the following day despite symptoms that had the potential to be life threatening out of concern for how they would be received in the ER; patients that have

experienced lengthy waits with little support; and frustrations that the patient and oncology team face judgements about the futility of treatment. These negative experiences create tense relationships between outpatient oncology and ER staff where conflict is common. In fact, one participant described how the clinic has 'given up' on education and resorted to 'communication' through incident reports.

There is growing discussion in the literature about the experience of stigma and palliative care citing how public and care provider perceptions serve as barriers to the provision of comprehensive comfort focused care (Cherny, 2009; Fadul et al., 2009; Morstad Bolt, Yusuf, & Himelstein, 2006). However, my personal sense is to be cautious about the implied judgement that is cast in using the word 'stigma' to describe this experience. Given the complexities that oncology nurses have shared about their experience of providing care in the outpatient clinic setting, it is quite likely that the experience of providing palliative care in the emergency context is just as complicated and multifaceted. An American study conducted by Heaston, Beckstrand, Bond & Palmer (2006) surveyed 169 emergency room nurses to learn about the obstacles and supportive behaviours for providing end of life care in the ER. Their study identified three primary barriers to end of life care including; heavy work load and competing care demands, discomfort dealing with angry and emotional patients and family members and a lack of space to provide privacy and sensitive care (p. 478 – 479). While this study provides some insight into the experience - and indeed, shared tensions with oncology nurses - there is a general lack of research in this area. Further research using qualitative approaches of inquiry to explore this lived experience would likely reveal a deeper understanding of this phenomenon.

To be clear, the observation that more research is required in this area is not a dismissal of these raised concerns. Without question, it is our responsibility within the nursing profession and within the health care community as a whole to commit to providing quality care in a way that is sensitive to the needs of families requiring care (CNA Code of Ethics, 2008). However, I propose that advances are achieved through teamwork. Improvements in patient care can only be realized when there is a willingness to seek to understand the experience of the other in finding common ground. Perhaps this is the value of phenomenological inquiry.

Cumulative Loss and the Burden of Witnessed Suffering

As described throughout this inquiry, the oncology nurse – patient/family relationship is pivotal to understandings of how the provision of non-curative care is experienced by oncology nurses in the outpatient cancer setting. In building relationships with patients and their families, oncology nurses come to learn of the patient's life and establish a form of professional intimacy. Participants frequently framed these relationships as the cornerstone of their practice and commonly spoke of the 'gift' or privilege of providing care to patients living with advanced cancer. Several described these relationships as transformative both personally and professionally, causing them to reflect upon their life, relationships and priorities. Many spoke of how these relationships reaffirm their sense of meaning and purpose in their role, providing sustenance to manage the emotional toll of their work.

The centrality of the nurse-patient relationship in the experience of providing care is reflected in other studies exploring the experiences of oncology nurses and hospice nurses providing care to oncology patients (Andrew & Whyte, 2004; Cohen & Sarter,

1992; Mcilfattrick, Sullivan & McKenna, 2006; Turner, Clavarino, Yates, Hargraves, Connors, & Hausmann, 2007). It would seem that there is a natural tendency to develop strong relationships with patients living with the physical and emotional vulnerability imposed by a diagnosis of advanced cancer and that oncology nurses frequently make 'personal connections' with patients as part of providing this care (Cohen & Sarter, 1992; Perry, 2008). Further, in keeping with experiences described within this inquiry, other studies have observed that the experience of establishing relationships with 'special patients' creates a willingness to go 'above and beyond' because there is a sense of personal and professional fulfillment of having 'been there' for someone who really needed you (Perry, 2008; Turner, Clavarino, Yates, Hargraves, Connors, & Hausmann, 2007). Interestingly, Turner et al. (2007) noted that 'senior' oncology nurses with more clinical experience tended to identify these emotional connections with patients as a way of coping with the emotional toll of witnessed suffering and loss (p. 152).

Perry (2008) made similar observations finding that 'exemplary oncology nurses' – that is to say oncology nurses that were identified by peers as role models – tend to avoid compassion fatigue (the emotional toll of witnessed suffering and loss) because the emotional toll of work is balanced with of the sense of meaning and personal / professional fulfillment derived from the close relationships established with patients and families. She goes on to challenge the commonly held assumption that compassion fatigue is attributed to 'caring too much' suggesting that the intrinsic rewards of the interpersonal realm of nursing practice may hold the key to mitigating the emotional burden of witnessed suffering (p. 91).

The study conducted by Perry (2008) provides a rich description of the central importance of the nurse-patient relationship when providing care to patients and families living with cancer and provides strong recommendations for how these relationships can be supported in nursing practice. However, I feel cautious about assumptions that may be made in suggesting that ‘exemplary nurses’ successfully avoid the impact of witnessed suffering. If asked, I would identify each of the nurses interviewed as part of this study as ‘exemplary’ as they have extensive experience and have reputations as mentors within their respective organizations. Yet, even as they described the ‘gifts’ of providing care, oncology nurses shared personal stories of loss, feelings of failure, and moral distress within their role. It seems clear that the nurse-patient relationship provides much of the balance in coping with witnessed suffering, however to suggest that it could be mitigated if the nurse only ‘cared enough’ would be an erroneous assumption that overlooks the complexity of the pieces of nursing work that contribute to the experience of emotional distress.

The emotional impact of witnessed suffering is real and a natural component inherent in the experience of vulnerability when establishing relationship with another. As Sarbo (2006) so eloquently states, “empathy becomes a double-edged sword for the nurse or clinician: on the one hand, empathy facilitates caring work; on the other hand, the act of caring leaves the nurse or clinician vulnerable to its very act” (p. 138). Oncology nurses often spoke about the difficulty in ‘shifting gears’ as the patient reaches end of life expressing feelings of sadness, wishing they could ‘do more’, and feelings of loss in the changing relationship as new care providers were introduced in the care team. The sharing or transition of care was experienced differently by different participants.

Some oncology nurses described 'being ok' with the idea of transitioning care to palliative care providers knowing that their patient would be 'well loved' and 'well cared for' in a manner that is consistent with their personal philosophy of care and confidence in the 'safety net' of palliative care services should the patient require admission to hospital. This was framed within the acknowledged reality that there is a new patient waiting to take their place in receiving treatment within the clinic. Others described a sense of loss, and a longing to remain involved in 'seeing the patient through' the final phase of illness and feelings of being 'disconnected' from care at the time when patients 'need you most'. Further, the experience of 'shifting gears' between patients who continue to receive treatment and have 'hope' for control and patients for whom treatment is no longer an option was described as a difficult task to balance. Participants frequently spoke of shielding their sadness in the moment - from other patients who may 'need a smile' and from colleagues to protect them from also 'breaking down' - to reconcile feelings of loss in privacy and at a later time.

Wakefield (2000) stated "For nurses who are regularly faced with caring for dying patients, grief is like a powder keg in that nurses may not be aware that they have been challenged by grief, but the effects of grief can be explosive and cause problems for practitioners at any time. Despite this, nurses are expected to carry on as normal once a patient has died. The notion of grief being like a powder keg is certainly appropriate for those nurses who have developed a close relationship with the patient as a result of having nursed them over an extended period of time" (p. 247). Although oncology nurses are commonly exposed to loss and witnessed suffering, research suggests that oncology nurses are reluctant to outwardly grieve in the presence of patients, families and

peers (Boyle, 2000; Feldstein & Gemma, 1995; Brown & Wood, 2009; Medland, Howard-Ruben & Whitaker, 2004; Saunders & Valente, 1994) and tend to ignore their own grief when caring for patients (Medland, Howard-Reuben & Whitaker, 2004). This has lead some authors to assert that nurses are socialized to believe that expressing these emotions is a display of unprofessionalism or a character flaw for becoming ‘too close’ to the patient and family (Feldstein & Gemma, 1995; Saunders & Valente, 1994).

A study conducted by Adams, Hershatter & Moritz (1991) exploring the phenomenon of accumulated loss among palliative care providers in an inpatient hospice setting revealed several themes that have particular relevance when thinking about the experiences described by oncology nurses in this inquiry. First, hospice nurses described an emotional void and lack of closure because of the inadequate opportunities to deal with loss in the context of the busy care environment (p. 30). This description of the emotional void seems to resonate with some participants description of loss in not having the opportunity to personally ‘see the patient through’ the final stage of their illness. Although oncology nurses in the ambulatory care setting are seldom witness to the actual death of a patient, the experience of loss through transition to other care providers or through death does not seem to be openly acknowledged within daily practice where there is a necessity to ‘move on’ in caring for the next patient.

Hospice nurses in Adams, Hershatter & Moritz’s (1991) study also expressed distress with contextual factors that created a divide between desired and actual clinical practice. This is in keeping with the distress described by oncology nurses in this study and other studies that have described the contextual constraints that inhibit the provision of holistic care (Andrew & Whyte, 2004; Mcilpatrick, Sullivan & McKenna, 2006).

Interestingly, Adams, Hershatter & Moritz (1991) note that this distress seems to become more palpable for nurses who have worked within the organization for a longer period. Further they found that “Registered Nurses (RNs) tend to expect too much of themselves and are overwhelmed with patient’s needs. They are bothered by feelings of inadequacy and guilt when work goals are not achieved” (p. 31). Further, nurses who worked more hours per week were found to make more personal sacrifices – including trouble leaving work on time and a tendency to skip lunch or breaks to do work - to ensure that patients receive the care they deserve (p. 31).

This finding strongly resonates with the experience of ‘defensive nursing’ and ‘heightened vigilance’ that some oncology nurses described their experiences providing care to patients living with non-curative illness. It seemed like the experience of personal sacrifice was particularly strong for nurses working within the primary (and largest) ambulatory cancer setting, whereas for oncology nurses working in community clinics, personal sacrifices seemed less of an imperative. One wonders if this variation in experience has something to do with the way that the community clinic is structured. Within the community outpatient cancer clinics oncology nurses seem to occupy a more blended role where the responsibilities for coordinating care and administering treatment are shared within the team. Oncology nurses working in this setting described gratitude that a resource nurse was readily available to ‘pitch in’ when a patient’s emotional or physical necessitated spending a longer period of one-to-one time with a particular patient. In contrast, oncology nurses working within a disease site model coordinating care described not having anyone to call upon for backup support when needed. This resulted to feelings in isolation (i.e. ‘you’re it baby’) and reinforces the imperative that

the nurse to shoulder primary responsibility to ensure that work gets done. It would seem that critical reflection about the organizational processes within the cancer setting may provide an opportunity to alter this dynamic and support oncology nurses in practice.

Finally, Adams, Hershatter and Moritz (1991) reported that hospice nurses experience diminished boundaries or a “blurring of personal and care-giving commitments” (p. 31) in the context of cumulative loss. Notions of boundaries are interesting and worth re-visiting because of the paradox described in literature exploring the oncology nurse – patient relationship. On the one hand oncology nurses are socialized to shield personal expressions of grief or loss because out of concerns that this might be perceived as unprofessional and that they have crossed a boundary in becoming ‘too close’ to a patient; yet on the other hand, it is within these close relationships that oncology nurses make meaning of their role and renewed sense of purpose to sustain future care of other patients. Given these competing tensions, how close is too close?

Some studies suggest that the skill of negotiating boundaries within therapeutic relationships is learned through experience. Totka (1996) found that nurses in their study had to ‘get it wrong’ before they could ‘get it right’. This research suggests that the experience of blurred boundaries is frequently experienced within practice but time and experience help the nurse to find their own ‘line’ when defining their personal boundaries (cited in Hawes, 2005, p. 16). A review of articles describing the symptoms of compassion fatigue, moral distress and burnout suggests that self reflection and attention to self care are key components to navigating boundaries and reframing perspectives to maintain the emotional energy to sustain nursing work (Absolon, & Krueger, 2009; Aycock, & Boyle, 2009). Strategies that have been suggested include intervention on the

personal level (for example personal self care behaviours such as diet and exercise, recreation, and self reflection) and those at the organizational level (team de-briefing rounds, peer support groups, coordinated activities that affirm the spiritual nature of work, and thoughtful program planning to mitigate contextual factors that inhibit caring relationships) (Aycock & Boyle, 2009, p. 187-191).

Participants in this study described a range of personal self-care activities that they find helpful in finding balance between the rewards and emotional toll of caring work. In keeping with Perry's (2008) study, many nurses described the oncology nurse – patient / family relationship as a source of strength citing the gifts of human connectedness and being witness to the resiliency of the human spirit. It seems that living close to death causes one to consider their own mortality and consciously recognize the gifts in every day. Having said this, oncology nurses also described the need to connect to others in their loss. Most frequently, connections with colleagues who share similar experiences (namely other oncology nurses) provide the primary source of this support. Some participants described participating in more structured grief work activities aimed at legitimizing and commemorating past losses. One such example is the memorial service described by one participant that was led by a spiritual care provider where the names of patients who had died were read, and nurses were called to reflect on the meaning of their work. This participant described feeling reluctant to participate in group grief work, perhaps reflecting the previously described phenomenon that nurses are socialized to grieve in private. However, she also described feeling '200% better' because she participated in this group. This leads one to think about how we incorporate loss and the emotional toll of witnessed suffering in oncology nurses work (and arguably,

in caring work in general). Supports that offer opportunity to engage in self care and shared grief work may assist oncology nurses in managing the loss inherent in their professional relationships with patients and families.

Summary

This study highlights the complexity of oncology nurses' daily work while providing non-curative treatment and care to patients living with advanced cancer in the ambulatory care setting. New and re-visited understandings about the primacy of the nurse patient relationship and natural tensions inherent in establishing professional intimacy and bearing witness to suffering and loss, the overarching desire to provide holistic care that is attuned to the physical and emotional vulnerability of patients and families living with advanced cancer and organizational structures that inhibit these efforts, the dynamic of bearing witness to hope and suffering while 'testing the water' to introduce the comfort care alternative while maintaining neutrality, and the moral distress experienced when 'patchwork' services fail to protect the patient who is receiving non-curative treatment from crisis all provide opportunities for further discussion about how these understandings inform practice. In the following chapter, implications for nursing practice and further, for building a 'culture of change' to support a blended palliative / oncology focus in care will be discussed in greater detail.

Chapter 6

Implications for Oncology Nursing Practice

Oncology nurses' experience of providing non-curative treatment within an outpatient cancer setting is extremely complex and multifaceted. Findings of this study suggest that within this experience, oncology nurses balance two simultaneous objectives that can sometimes be in odds with one another in their vigilance to attend to both the emotional and physical safety of patients receiving non-curative treatment. On the one hand, the oncology nurse seeks to preserve and respect their patient's hope for prolonged survival with continued non-curative treatment, and on the other, oncology nurses struggle to 'keep it real' by revisiting treatment decisions in the context of witnessed suffering and trying to construct a 'back up plan' to rescue patients should they run into crisis in the community. Within each of these objectives lie inherent overlapping tensions that are shaped by the various conceptualizations of how both cancer care and palliative care are understood, how treatment decisions are framed within their care team, and organizational constraints in the provision of services in the community.

Oncology nurses have a pivotal role in navigating these tensions with the patients and families for whom they are providing care. Further I propose that oncology nurses' shared philosophy of practice and commitment to providing holistic care is closely linked to conceptualizations of palliative care making oncology nurses natural leaders in the 'culture shift' to integrate palliative care approaches as an integrated part of the cancer continuum. The following discussion will highlight and build upon possibilities raised through the interpretation of oncology nurses experience and suggest how they might support oncology nursing practice in providing non-curative care.

Having said this, I think it is important to be clear in stating that strengthening support of oncology nursing practice is but one piece of a greater puzzle in building this shared 'culture of care'. This study clearly illustrates some of the organizational and systemic realities that challenge care providers' ability to provide holistic care in the ambulatory cancer setting and the apparent disconnect that exists between oncology and palliative care specialties because of these limitations. When thought of in this context, it becomes clear that changing the 'culture of care' is ultimately a community effort.

Re-thinking the Context of Practice

Oncology nurses in this study frequently spoke of the organizational constraints both within the ambulatory care setting and in the provision of services in the community as significant barriers in their attempts to provide holistic patient / family centered care. These understandings provide an opportunity for further discussion and stakeholder collaboration to re-evaluate and possibly challenge practice norms that 'get in the way' of integrating palliative care throughout the care of patients receiving non-curative treatment for their illness.

Oncology nurses working within smaller community cancer clinics often described how the context of their particular care environment enabled them to practice as a team while providing care to patients living with advanced cancer. They described having roles within the clinic in both coordinating care and administering treatment and the availability of a resource nurse that is readily available to 'pitch in' when a nurse is called to invest time with a particular patient who has complex physical or emotional needs. Within the context of this model of care, oncology nurses expressed feelings of being supported in their daily work and confidence that their team members would ensure

patients would receive the care they need, even if that nurse was not personally available to provide the care. This seems to be in contrast with the heightened vigilance (i.e. 'defensive nursing') and isolation (i.e. 'you're it baby') described by oncology nurses working in larger ambulatory care settings. This observation raises interesting possibilities when considering oncology nursing roles within the clinic and processes that might support teamwork in daily practice. One wonders if the availability of having a colleague to call upon to 'pitch in' would help to mitigate some of the distress that oncology nurses experience when they are pulled in multiple directions and require time to attend to the emotional / psychosocial aspects of a patient's experience.

Further, it would seem that in keeping with other studies exploring oncology nursing in the outpatient care setting, processes that constrain the space and time available to provide holistic care create an environment where oncology nurses must choose between 'nursing the clinic' or 'nursing the patient'. In the context of a busy clinic with limited space, a large number of patients waiting to be seen, and limited time to attend to their concerns, participants expressed feeling more like a 'traffic controller' than a nurse. These constraints sometimes prompt oncology nurses to purposefully decide to avoid 'clinic' as a time to address the emotional and psychosocial concerns of patients and families because of the time these discussions require and distress of having to 'pick up the emotional pieces' when there is little opportunity to do this in a meaningful way. Ironically, 'clinic' time is generally the only time that there is dedicated time and space to attend to those discussions in the presence of the oncologist. This has particular importance when considering the role that oncologists have in leading discussions about prognosis, what might be anticipated as the disease progresses, and

advance care planning in preparation for end of life. Further, avoiding the discussion in clinic creates the necessity of having these discussions with the nurse in locations that often do not provide much privacy. Participants who described this experience lamented that there ought to be space available for nurses to conduct assessments and sensitive goals of care discussions that affords privacy, even if this is ‘just a nursing’ function. It would seem that processes that only attend to the work of one member of the team have the potential to make some feel that the oncology nursing role is less valued. Given these findings, it would seem that critically appraising clinic processes with invested stakeholders (oncology nurses, physicians, clerical staff, and patients and families) may offer new ideas of how care might be delivered in a way to support holistic / palliative care.

Systemic constraints external to the oncology cancer setting were also frequently described as barriers to implementing palliative care earlier in the care of patients living with advanced cancer, particularly when patients continue to receive non-curative therapy to control their disease and its symptoms. Oncology nurses commonly spoke about the appropriateness of facilitating patient connections with palliative care providers early in the course of illness. Further, oncology nurses trust that palliative care providers share a philosophy of care that both acknowledges and pays special attention to the physical, emotional and social vulnerabilities of patients and families living with advanced cancer. However, access to coordinated care services is constrained by patient and family decisions to pursue ongoing disease focused treatment. As a result, oncology nurses must construct a network of ‘patchwork’ supports to protect the vulnerability of patients and

families who are struggling with the growing burden of advanced cancer and its treatment in the community.

Oncology nurses expressed their frustration about being caught between services when trying to coordinate care and their personal sense of injustice that patients who are seeking treatment in the hopes of controlling the disease or ‘buying time’ are excluded from services offered through coordinated palliative care programs. This sense of injustice seems amplified by the inconsistencies that exist between the urban health region and surrounding rural health regions that allow concurrent chemotherapy treatment and palliative care services.

These understandings have implications when thinking about the structure of palliative care services that might be applied at the regional, provincial and national level. At the regional level I think it is important to have conversations about the inconsistency that exists in enrolment criteria between urban and rural settings. This inconsistency seems to add to the confusion within the oncology community and arguably the greater community as a whole about what might be expected when one receives ‘palliative care’. Perceptions of injustice may be appropriate if a patient who is receiving non-curative chemotherapy and lives twenty minutes outside of the city is ‘eligible’ for enrolment to rural coordinated services while similar patients living within the city are restricted from accessing these services. Although each health region has its own unique priorities in providing health care to its community and deciding how services are funded, there is room for leadership and a need for funding at the provincial level to create a unified vision of what palliative care ‘ought to be’. By extension, there is a need for leadership

and funding at a national level to create a national vision of palliative care and raising it as a priority in providing quality health care services to Canadians.

Re-thinking the Oncology Nursing Role in Goals of Care Discussions

Oncology nurses have an important contribution to make in raising the focus of quality of life in patient and family decision making about treatment and goals of care. Through relationship, oncology nurses are witness to the patient and family's construction of their personal story of cancer and how they integrate this story within their lives. Oncology nurses become a trusted resource to patients and families and are witness to the subtle burdens experienced through the course of their disease and its treatment. These changes not always readily recognized or acknowledged by patients, families, or their oncologists. As a result, oncology nurses frequently 'test the water' to get a sense of a patient's goals of care within the context of balancing hope and suffering. If oncology nurses perceive cues from the patient or their family that the burden of treatment is becoming harder to manage, or an interest in discussing alternatives, they will readily take that opportunity to re-evaluate goals of care.

Having said this, there is concealed dynamic within oncology nurses' understanding of their role in these discussions that provides an opportunity to re-evaluate practice. Although most participants in this study identified that they have a key role in the ongoing discussions about goals of care throughout their relationship with a patient and family, the approach described in having those discussions seemed to depend on the context of the situation (i.e. perceived readiness of the patient), the context of their relationship with the oncologist, and their perceived role within the clinic. Some participants described situations where they would have direct involvement in these

discussions, for example discussing goals of care, quality of life and the impact of treatment as part of the oncologist / patient visit within the clinic, while others described situations where a 'softer approach' was used. In these situations participants described 'raising the alternatives' in a way that would not 'overstep bounds' in the hopes that empowering patients with information about their disease and alternative treatment options families might be empowered to discuss those alternatives with the oncologist. Further, it would seem that the oncology nurses' perceived role within the care team in having these discussions and the approach used by the oncologist when discussing the non-curative nature of the illness at diagnosis sets the tone for how these discussions are carried through the course of non-curative treatment. Several participants described avoidance of 'palliative' language within the clinic prompting the use of 'chronic' or 'control' language when discussing the intent of treatment. Ambiguity about the degree of candour used when discussing prognosis or the extent to which the patient and family absorbed this information frequently prompted a 'softer approach' when gauging readiness to discuss stopping disease focused treatment.

It would seem that for participants in this study, the experience of providing care to patients who continue to 'fight' in the hope of a miracle, and having witnessed past miracles with other patients, prompts oncology nurses to check their assumptions about the futility of treatment and respect the hopes of the patient - even in the context of witnessed suffering. In witnessing these miracles, oncology nurses default to a non-judgmental 'who am I to say' position and take care to remain neutral when presenting options.

Literature describing: the nature of hope and possibilities for maintaining hopefulness despite the limitations of treatment to control disease, the need for honest information about prognosis and what is expected as the disease progresses to make balanced treatment decisions, and the appropriateness of health care providers 'weighing in' on decision making challenge some of the dynamics described in current practice. It could be argued that the practice of maintaining neutrality may not be appropriate for the oncology nurse or the oncologist. The practice of 'never saying no' if a patient wants to 'keep fighting' with chemotherapy in situations where it is unlikely to be of benefit is difficult to support as best practice. Although the ethical principles of autonomy and a refusal to be paternalistic may be argued in supporting this approach, 'abandoning the patient to their autonomy' is equally harmful (Lowery, 2005). Further, although some oncology nurses may seek to empower patients by raising the possibility of alternative approaches to managing the illness and symptoms (i.e. palliative care) and encouraging patients to discuss this with the oncologist, more direct approaches(i.e. 'weighing in' on decision making) may be warranted. It is possible that patients and families feel inhibited in raising this discussion independently with the oncologist for fear of what this might mean or in hope that there is 'still something to be offered'. It is within the scope of ethical nursing practice to ensure that decision making is informed (CNA code of ethics, 2008). Oncology nurses are in a position to ensure that quality of life is the central focus of informing these decisions.

While it is important for oncology nurses to actively participate in goals of care discussions, this may not feel comfortable if this has not been the traditional approach used in practice. Many of the oncology nurses within this study described having learned

to have difficult discussions by witnessing skilled clinicians role-model effective communication. One wonders if this presents an opportunity for linking the oncology and palliative worlds with the integration of a palliative care advanced practice nurse role in the ambulatory care setting. Emerging research seems to suggest that the integration of this role improves patient mortality and can significantly decrease the odds of being hospitalized (Prince-Paul, Burant, Salzman, & Matthews, 2010). Further, the availability of a nursing resource who is knowledgeable about the interconnected services in the community and models skill in having difficult discussions may support oncology nurses in developing similar skills within their clinical practice. Given how oncology nurses in this study described acquiring skills through mentorship and practice, this seems to be a plausible opportunity to consider.

Re-thinking Crisis

The witnessed fragility of patients through the course of non-curative treatment as a result of the cumulative effect of progressive illness and treatment toxicities was described by many oncology nurses to be precipitating factor when they did ‘weigh in’ on decision making. In light of these witnessed changes, oncology nurses frequently described actively questioning the role of further treatment with patients, families and the oncologist. Within this experience is a desire to protect the patient from harm in the community, recognizing the patient’s vulnerability and the growing likelihood of crisis because of growing symptoms or challenges managing care at home. Enrolment to coordinated palliative care services was perceived by many to be a comprehensive ‘safety net’ in managing the inevitable crisis and sparing the patient and family a distressing trip to the emergency room. However, access to coordinated palliative care services is

restricted to those who have decided to forgo further treatments to control their disease. As a result, oncology nurses must construct a network of ‘patchwork’ of supports for patients who desire further non-curative treatment.

As mentioned in the previous chapter, oncology nurses expressed feelings of distress and of having ‘failed’ patients when this ‘patchwork’ of services failed to prevent crisis and protect the patient from having to go to the emergency room. Within this, oncology nurses shared powerful stories of negative past encounters and described strained relationships with emergency room staff. Several spoke about the perceived ‘stigma’ of being an oncology patient and expressed feelings of frustration that oncology patients are not valued as ‘worthy’ of seeking care in the emergency room in times of crisis. These accounts strongly suggest a need for further research and discussion about how oncology patients perceive care when accessing urgent care through the emergency room in times of crisis. As mentioned previously, the creation of a shared culture of care that attends to the holistic emotional and physical needs of patients and families receiving care requires the commitment and involvement of the greater community. A scan of current literature suggests that very little is known about how emergency room clinicians perceive oncology and palliative care, or the challenges experienced when providing this care in practice. Given that both oncology nurses and patients seem attempt to avoid the ER at all costs and concerns that oncology patients are ‘written off’ as palliative when accessing care, it would seem important to learn more about how the emergency team experiences providing care to ‘oncology’ or ‘palliative’ patients and whether there is a difference or distinction between the two. Given the complexity of experience shared in

this study, it is likely that the experience of colleagues in the emergency room setting is just as complex.

I suggest that judgements and assumptions are a natural part of how all people experience life – like culture, they provide a framework through which we understand all that is around us. Further, it is through authentic interest or a willingness to be open to understanding the other that these assumptions are challenged. For example, someone reading this research may discover subtleties in oncology nursing practice that they had not previously considered making it less difficult to appreciate that experience. Further, one might argue that progress in building relationships between two teams is hampered when these assumptions are accepted without critical reflection about the hidden understandings that influence experience. Perhaps research that employs a phenomenological approach similar to the one used in this inquiry to explore the meaning and experience of providing oncology / palliative care in the emergency room might reveal new opportunities for understanding and finding common ground.

Finally, the notion that an emergency may not really be an emergency bears further discussion when thinking about how practice might be supported to build a more durable ‘safety net’ and reduce the need for urgent care. As mentioned previously, emergencies are traditionally described as an unforeseen and sudden event. Given previous discussions about the often predictable course of decline in the final months and commonality in the symptoms and challenges experienced in the final months / weeks of life, it would seem that much of what is experienced by patients and families in the final months and weeks of living with an advanced malignancy can be anticipated in advance.

Preparing patients and families for what might be expected as the disease progresses and having candid discussions about goals of care and the approach that ought to be used to manage them is traditionally part of the comprehensive focus of palliative care. Advance care planning, and talking about the ‘what if’ scenarios in anticipation of the symptoms and care needs that are likely to develop with progression of advanced cancer illness forms a key component of planning for end of life. However, research suggests that prognosis and what might be expected in the final stages of illness are infrequently raised by oncologists in discussions with their patients (Daugherty & Hlubocky, 2008; Finlay & Casarett, 2009; Koedoot, Oort, de Haan, Bakker, de Graeff, & de Haes, 2004) . This may attribute to research findings reporting that advance care planning is rarely discussed within in oncology practice (Bradley et al., 2006; Levin et al., 2008).

Oncology nurses in this study shared similar experiences observing that ‘even though the patient is dying, they really aren’t dying’. It would seem that when a person is receiving disease focused treatment it is perhaps easy to forget (or put off thinking) that the illness will ultimately result in death. Most frequently participants described discussing advanced care planning only when the patient receiving non-curative treatment made the decision to stop. Further, oncology nurses observed that if the decision to stop chemotherapy is not made, anticipatory planning for a death at home is not discussed. The poignant stories shared by one participant about the traumatic experiences of patients who died in the community without having these discussions (and the distress of the families and nursing staff in these situations) are testament to the

importance of this kind of planning. Further, they provide opportunities for re-evaluating practice.

It would seem that the area of advanced care planning provides an opportunity for collaboration between oncology and palliative care specialties. Oncology clinicians have developed expertise in the management of non-curative treatment and the side effects of therapy whereas palliative care clinicians have developed expertise in communication with families about prognosis, goals of care, and what might be expected in preparation for the final months / weeks of life. Shared education and perhaps opportunities to witness one another in practice may provide opportunities to learn from one another in developing these skills. Thinking more specifically about nursing practice, one wonders if having joint oncology / palliative care rounds in the community would help to facilitate communication between the two specialties. These rounds might provide an opportunity for oncology nurses to share information about patients for whom palliative care services may be of benefit with the palliative care team. In return, the palliative care team might share information about the care of patients for whom oncology nurses have provided care but have since 'transitioned' to palliative care services. This sharing of knowledge has potential to inform the care plan of specific patients, but perhaps more broadly, it would also foster greater familiarity and a stronger working relationship. Further, it may assist with 'closing the loop' so that oncology nurses are not left out of the experience of providing care to their patients in the final phase of life.

As mentioned in the previous chapter, patient question prompt sheets and decision aids have been shown as effective strategies to encourage patients and families to raise discussions about prognosis, goals of care, and what might be anticipated as the disease

progresses with the oncologist (Brown, Burtow, Dunn & Tattersall, 2001; Bruera et al., 2001; Glynne-Jones et al., 2006; Harrington & Smith, 2008; Leighl, Butow & Tattersall, 2004). However, in keeping with thoughts proposed in earlier discussions, there is a joint responsibility for oncologists and oncology nurses to anticipate these questions and actively raise them in discussion. Raising the topic and inviting feedback from the patient / family about how much information they would like to know is described as a strong strategy for maintaining hope and honesty while legitimizing questions and further discussion about quality of life and goals of care (Finlay & Casarett, 2009).

Finally, it may be unrealistic to expect that all crisis events can be planned for in advance or managed in the community avoiding acute inpatient care. Clearly, current statistics of the utilization of inpatient palliative care services and growing demand for residential hospice care suggests that a home death is not possible for all families to support. When thinking about what oncology nurses perceive to be missing when patients have not transitioned to coordinated palliative care services in light of their decision to continue with non-curative treatment, it seems that limited access to inpatient supports present a significant challenge. In the absence of alternatives, oncology nurses are obligated to advise patients to seek care in emergency to the distress of the patient, family and nurse. This suggests a need for further discussion among stakeholders and perhaps the creation of an inpatient alternative where patients receiving non-curative treatment can receive the support they require.

Re-visiting Loss

The emotional impact of witnessed suffering and loss is real and a natural component inherent in the experience of vulnerability when establishing relationship with

another. The oncology nurse – patient/family relationship is pivotal to understandings of how the provision of non-curative care is experienced by oncology nurses in the outpatient cancer setting. In building relationships with patients and their families, oncology nurses come to learn of the patient's life and establish a form of professional intimacy. Participants frequently framed these relationships as the cornerstone of their practice and commonly spoke of the 'gift' or privilege of providing care to patients living with advanced cancer. Several described these relationships as transformative both personally and professionally, causing them to reflect upon their life, relationships and priorities. Many spoke of how these relationships reaffirm their sense of meaning and purpose in their role, providing sustenance to manage the emotional toll of their work.

Yet, even as they described the 'gifts' of providing care, oncology nurses shared personal stories of loss, feelings of failure, and moral distress within their role. It seems clear that the nurse-patient relationship provides much of the balance in coping with witnessed suffering, however it does not negate the reality of loss experienced or the need to manage those losses.

Having said this, the oncology nurses seem to make meaning of this loss in their own unique way. Some spoke about the difficulty in 'shifting gears' as the patient reaches end of life expressing feelings of sadness, wishing they could 'do more', and feelings of loss in the changing relationship as new care providers were introduced in the care team. Within this experience, oncology nurses expressed a strong desire to remain involved in 'seeing the patient through' the final phase of illness and feelings of being 'disconnected' from care at the time when patients 'need you most'. Others described 'being ok' with the idea of transitioning care to palliative care providers knowing that

their patient would be ‘well loved’ and ‘well cared for’ in a manner that is consistent with their personal philosophy of care and confidence in the ‘safety net’ of palliative care services should the patient require admission to hospital. Although oncology nurses seem to have different perspectives about the meaning of loss experienced in times of service transition, there was a universal acknowledged reality that there is a new patient waiting to take their place in receiving treatment within the clinic.

Oncology nurses commonly described how attending to ‘new’ patients who are receiving treatment in the hopes of controlling disease while also attending to patients for whom this is no longer a possibility can be an emotionally difficult task. The experience seems to prompt the nurse to ‘shift gears’ between one patient and the next, almost as though the oncology nurse is required to be different for different people. As one participant described “As a nurse, you learn how to give bad news or sit with somebody who is dying and then walk out the door and put your smile on for everybody else that’s there who needs that smile (tears). Even though you don’t feel like doing it, and you don’t want to do it, but you have to” (Participant 3). This quote is a poignant example of how oncology nurses feel obligated to shield their sadness in the moment - from other patients who may ‘need a smile’ and from colleagues to protect them from also ‘breaking down’ - to reconcile feelings of loss in privacy and at a later time. This is consistent with earlier discussions describing how oncology nurses are socialized to believe that outward display of such emotion is unprofessional or evidence of a personal flaw in the nurse for having become ‘too close’ to a patient. In the moment, nurses tend to suppress loss to stay strong for others. However, research highlighting the negative consequences of

unresolved moral distress, compassion fatigue and burn out suggests that oncology nurses require opportunity to integrate losses into their life.

Participants in this study described a range of personal self-care activities that they find helpful in finding balance between the rewards and emotional toll of caring work. In keeping with Perry's (2008) study, many nurses described the oncology nurse – patient / family relationship as a source of strength citing the gifts of human connectedness and being witness to the resiliency of the human spirit. It seems that living close to death causes one to consider their own mortality and consciously recognize the gifts in every day. Having said this, oncology nurses also described the need to connect to others in their loss. Most frequently, connections with colleagues who share similar experiences (namely other oncology nurses) provide the primary source of this support. Some participants described participating in more structured grief work activities aimed at legitimizing and commemorating past losses. One such example is the memorial service described by one participant that was led by a spiritual care provider where the names of patients who had died were read, and nurses were called to reflect on the meaning of their work. This participant described feeling reluctant to participate in group grief work, perhaps reflecting the previously described phenomenon that nurses are socialized to grieve in private. However, she also described feeling '200% better' because she had participated in this group.

These findings suggest the importance of thoughtfully considering how oncology nurses are supported to incorporate loss and the emotional toll of witnessed suffering in daily practice. Supports that offer opportunity to engage in self care and shared grief work may assist oncology nurses in managing the loss inherent in their professional

relationships with patients and families. Research in this area suggests several strategies that might be used to legitimize and acknowledge loss. Lally (2005) found that integrating discussion about the emotional impact of caring work as part of patient care rounds provided nursing staff opportunity to recognize that they are not alone in their experience. Group grief work activities such as the one described earlier have also been described as helpful reflective practices. Aycock & Boyle (2009) describe how ceremonial recognition of the spiritual aspect of caring has been used in some centers to help to recognize the importance work of professional caregivers (p. 188). Ceremonies led by chaplaincy staff such as the 'blessing of hands' where a simple prayer is said for the continued gift of caring for others, or "tea for the soul" retreats in the work day can help attend to the self care needs of staff (p. 188). Peer support is also recognized as one of the more common forms of support sought by nursing staff. Sharing grief with others who understand is a powerful way for nurses to vent the emotions of their work and recognize they are not alone in their experience. However there is also an argument that peer support may not be sufficient in isolation of other self care activities. Peer support sessions led by a skilled facilitator may be more therapeutic and increase the likelihood that patterns of thinking may be challenged for deeper reflection rather than simply repeating usual responses (Aycock & Boyle, 2009).

Palliative care nurses working in the community in the urban health region meet every two weeks to engage in debriefing rounds. Within these rounds palliative care nurses share some of the challenging encounters they have experienced and the emotional toll of work. These sessions are also attended by other members of the regional interdisciplinary team providing an opportunity for raising new perspectives in making

sense of loss. These rounds are highly valued and well attended, in part because it has been normalized and legitimized as an important part of community nursing work. One wonders if similar models may be employed within the ambulatory cancer care setting to support oncology nurses in their practice.

Closing Comments

I began this study by exploring my personal experience of coming to the question and declaring the personal assumptions that shaped how I approached this work. It seems fitting to conclude by reflecting on what I am taking away from what I have learned. I find it difficult to write a conclusion to this work because it feels far from finished. In essence, it is an invitation for further discussion and debate. This study builds upon past understandings and reveals new understandings about oncology nurses' experience providing non-curative care within the outpatient setting. It provides a new appreciation for the complexity of oncology nurses work and new opportunities to support oncology nursing practice. I believe that oncology nurses' shared philosophy of practice, close relationships with patients and families, and their commitment to providing holistic care positions them as important leaders in making the vision of integrated oncology / palliative care a reality. Achieving this reality requires the commitment and involvement of the greater community and I would argue that appreciation for the multiple realities of how this care is experienced provides a strong foundation for this debate. Finding common ground and realizing a shared vision requires appreciation for the experience of others. I think this is the true value of this research.

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Appendix A

Letter Requesting Site Permission to Conduct Research

Sent to the Research Impact Committee and Director of Nursing of each site

To Whom it May Concern:

My name is Lisa Streeter and I am a graduate student in the Advance Practice Leadership distance education program at the University of Victoria, School of Nursing. I am writing to request permission to invite oncology nursing staff in your facility to participate in a master's thesis qualitative research study exploring how oncology nurses experience providing non-curative treatment and care in an outpatient oncology setting. Much of what has been written suggests that distinctions between what has traditionally been considered 'palliative' and 'curative' care are blurred when patients receive treatment for advanced disease. While an integrated model of palliative care delivery is increasingly viewed to be an important part of comprehensive cancer care, services provided through formal palliative care programs are often limited to those who have an identified prognosis of less than 6 months and whose treatment goals are consistent with services offered under those programs (i.e. no chemotherapy, no CPR).

Little is known about the experiences of oncology nurses providing palliative care to families living with advanced cancer who seek treatment aimed to slow the progression of advanced disease. I propose to explore the lived experience of oncology nurses who coordinate care and / or administer treatment to persons receiving palliative intent treatment in a wide range of clinical settings. To that end, I am requesting permission to invite nurses who are employed at the following agencies; Cancer Care Manitoba (St. Boniface and Mc Charles sites), and the Winnipeg Regional Health Authority (community cancer clinics at Grace General Hospital, Seven Oaks General Hospital, Concordia General Hospital and Victoria General Hospital) to participate in this research.

Specifically, I am requesting permission to:

- Post advertisements inviting oncology nurses to participate in this study
- Request that staff distribute information about the study (via email or printed material) on my behalf
- Contact nurses whom I know through my current nursing position in the Winnipeg Regional Health Authority Palliative Care Program.

It is anticipated that findings of this study will lead to a greater understanding of the complexity of delivering palliative cancer care in an outpatient setting and provide new insight into how a blended palliative / oncology focus of care might be supported in practice.

Please find attached an information letter summarizing the proposed study design. I welcome the opportunity to discuss this exciting project with you and look forward to your reply.

Sincerely, Lisa Streeter, RN (with contact information)

** Information Letter (Appendix B) and Poster (Appendix C) sent with this correspondence*

Appendix B

Invitation to Participate in Study



Walk a mile in your shoes?

How do oncology nurses experience providing palliative care to families living with advanced cancer who seek treatment aimed to slow the progression of advanced disease?

If you are an oncology nurse who coordinates care or administers treatment you are invited to participate in a University of Victoria, master's thesis qualitative research study exploring how oncology nurses experience providing non-curative treatment and care in an outpatient oncology setting. Participation is voluntary.

As part of this study you would participate in an audio-taped 60 to 90 minute interview, at a time and location of your choice (outside of working hours) discussing situations where you have provided palliative care, how that was experienced as part of a team, and what you perceive to be facilitators and barriers in your practice.

You have an opportunity to participate in important discussions regarding palliative care situations that have meaning in your clinical practice. Your contribution is invaluable to the success of this research.

For more information, please contact:

Lisa Streeter RN (graduate student, U Vic)	Project Supervisor: Marjorie McIntyre
Email:	Email:
Phone:	Phone :

Appendix C

Study Information Letter

Project Title: How do oncology nurses experience providing palliative care to people seeking non-curative chemotherapy treatment?

Principle Investigator: Lisa Streeter, RN, graduate student of the University of Victoria, School of Nursing.

Phone:

Email:

Project Supervisor: Marjorie McIntyre, RN, PhD

Phone:

Email:

Summary of Project:

Purpose: Much of what has been written suggests that distinctions between what has traditionally been considered ‘palliative’ and ‘curative’ care are blurred when patients receive treatment for advanced disease. While an integrated model of palliative care delivery is increasingly viewed to be an important part of comprehensive cancer care, services provided through formal palliative care programs are often limited to those who have an identified prognosis of less than 6 months and whose treatment goals are consistent with services offered under those programs (i.e. no chemotherapy, no CPR). Little is known about the experiences of oncology nurses providing palliative care to families living with advanced cancer who seek chemotherapy treatment aimed to slow the progression of advanced disease. What do oncology nurses think of and how do they talk about ‘palliative care’? How is providing palliative care experienced as part of a team? What do oncology nurses perceive as facilitating or hindering delivery of palliative care in their practice?

Study Subjects: Oncology nurses who coordinate care or administer treatment to persons receiving palliative intent chemotherapy treatment for advanced cancer will be invited to participate from a wide range of clinical settings including: Cancer Care Manitoba (St. Boniface and Mc Charles sites), and the Winnipeg Regional Health Authority (community cancer clinics at Grace General Hospital, Seven Oaks General Hospital, Concordia General Hospital and Victoria General Hospital).

Informed Consent: Ethical approval for this study has been granted via the University of Victoria Human Research Ethics Board and approval through the University of Manitoba Research Ethics Board is pending. Written informed consent to participate in this qualitative study will be obtained from consenting participants. The investigator will answer any questions about this study and review measures taken to ensure participant anonymity and confidentiality both verbally and in writing prior to initiation of the interview. Participants will be encouraged to read the consent form carefully prior to signing and encouraged to ask questions at any time. Participation in this study is voluntary and withdrawal is possible at any time without penalty.

Procedure: As a participant you will be invited to participate in a 60 to 90 minute interview, at a time and location of your choice, discussing situations where you have provided palliative care, how that was experienced as part of a team, and what you perceive to be facilitators and barriers in your practice. Following the interview, you will be asked to complete a demographic questionnaire which will be coded to the transcript but not identified by name.

Anonymity / Confidentiality / Security of Information: Audio cassette recordings will be transcribed by the principle investigator. These transcripts will be reviewed with audio recordings to ensure accurate transcription of data. All identifiers will then be removed and pseudonyms will be inserted. Audio recordings, transcripts and consent forms will be secured in the principle investigator's personal office. All data will be destroyed within three years of completion of the research study.

Data Interpretation: Transcripts will be interpreted using methods consistent with a phenomenological approach to qualitative research. Each interview will be analyzed as its own story and will contribute to the overarching analysis which will capture the essence of oncology nurse's experience of providing palliative care in an outpatient oncology setting. The project supervisor and project committee members will provide guidance and support throughout this process.

Use of Data: Data obtained through this process will be used solely for the purposes outlined in this research study.

Feedback: Results of this project will be shared with the participants of the study and the participating agencies in the form of presentations and written reports. Results will be submitted for publication in various academic research journals. Additionally, findings may be presented at professional conferences nationally and internationally

Appendix D

Participant Consent Form

**Reviewed, discussed, and completed prior to initiating the interview*

Title: How do outpatient oncology nurses experience providing palliative care to people living with advanced cancer receiving non-curative chemotherapy treatment?

You are invited to participate in a qualitative master's thesis study that is being conducted by Lisa Streeter under the guidance of her supervisory committee, Marjorie McIntyre, RN, PhD, and Carol MacDonald, RN, PhD. As part of this study, you will have opportunity to discuss situations where you have provided palliative care, how that was experienced as part of a team, and what you perceive to be facilitators and barriers in your nursing practice.

Lisa Streeter is a graduate student in the University of Victoria, School of Nursing. You may contact her if you have any questions regarding this research by phone at (204) 452-7371 or by email at: lstreete@uvic.ca . Questions about this study may also be directed to members of the supervisory committee overseeing this project:

Project Supervisor:

Marjorie McIntyre, RN, Ph D

Phone:

Fax:

Email:

Committee member:

Carol McDonald, RN, Ph D

Phone:

Fax:

Email:

As a graduate student, I am required to conduct research as part of the requirements for a degree of Master of Nursing in the Faculty of Human and Social Development.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information that is not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose: The purpose of this research project is to explore oncology nurses' experiences providing palliative care to those diagnosed with advanced cancer who seek non-curative treatment aimed at slowing disease progression. I am seeking the perspectives of oncology nurses who coordinate care or administer treatment in a variety of outpatient cancer treatment settings. How do nurses experience palliative care in their everyday practice? How is this experienced as part of a team? What are some of the perceived supports and barriers to palliative care in their practice?

Significance: Research of this kind is important because much of what has been written suggests that distinctions between what has traditionally been considered ‘palliative’ and ‘curative’ care are blurred when patients receive treatment for advanced disease. While an integrated model of palliative care delivery is increasingly viewed to be an important part of comprehensive cancer care, services provided through formal palliative care programs are often limited to those who have an identified prognosis of less than 6 months and whose treatment goals are consistent with services offered under those programs (i.e. no chemotherapy, no CPR). Little is known about the experiences of oncology nurses providing palliative care to families living with advanced cancer who seek treatment aimed to slow the progression of advanced disease.

Procedure: You are being asked to participate in this study because you are an oncology nurse who either coordinates care or administers treatment in an outpatient community cancer center. If you agree to voluntarily participate in this research, your participation will include a 60 – 90 minute interview where you will have opportunity to discuss situations where you have provided palliative care, how that was experienced as part of a team, and what you perceive to be facilitators and barriers in your nursing practice. If you agree to participate, the interview will be conducted at a time and place that you find convenient. The interview is expected to last 60 – 90 minutes but may exceed this time limit if you are interested in continuing the discussion. You will be asked to complete a demographic questionnaire following your interview which will be coded to the transcript but not identifiable by name.

Potential Risk / Burden: Participation in this study may cause some inconvenience to you, including an investment of one to one and a half hours of your time. As a participant in this research, you will be asked to reflect upon experiences where you have provided care to people receiving non curative treatment. While talking about those experiences can provide an opportunity for better understanding of what is often ‘taken for granted’ as part of daily practice, it may also create feelings of discomfort or distress. You are under no obligation to continue with any line of questioning with which you are uncomfortable. You are also free to leave the interview and withdraw from the study without penalty. If our discussion elicits emotions or concerns that are troubling, the Employee Assistance Centre is available to provide support.

The Employee Assistance Centre (EAC) provides assistance to health care staff and their families throughout Manitoba. Counselling services are available without charge in a variety of areas including: relationship, family, addictions, stress, financial, career, pre-retirement, and health promotion. Additional services include crisis intervention, information services, and library resources.

Confidentiality is the most important aspect the Employee Assistance plan. To access services, you do not have to notify your employer or anyone in your facility. You or your family members can call the Blue Cross Employee Assistance Centre 24 hours a day, 7 days a week.

If you would like to speak with a counselor or learn more about the services offered through this health benefit program, please see the following websites or call (204) 786-8880 or toll free 1-800-590-5553.

<http://www.wrha.mb.ca/professionals/eap/index.php>
www.mb.bluecross.ca

Potential Benefits: The potential benefits of your participation in this research include an opportunity to palliative care issues that have meaning in your clinical practice. It is through reflection upon past experiences that nurses find new opportunity to challenge status quo and improve patient care. You have an opportunity to contribute to a better understanding of how palliative care translates into daily clinical practice. This is an important first step in identifying how a blended palliative / oncology focus of care might be supported in practice.

Compensation: There is no form of compensation for this study. Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you withdraw from the study your data will not be used in data interpretation.

Disclosure of Possible Conflict of Interest: You may have a relationship with me as a colleague or friend or in my employed capacity as a clinical nurse specialist with the Winnipeg Regional Health Authority Palliative Care Program. This research is in no way affiliated with or connected to my employed role. You should not feel coerced to participate in this study. If you feel obligated to participate, you should decline from this research.

Anonymity / Treatment of Data: In terms of protecting your anonymity, audio cassette recordings of sessions will be personally transcribed verbatim. Transcripts will then be reviewed in tandem with the audio recordings to assure accuracy. All identifiers will be removed and pseudonyms will be inserted. Draft copies of transcriptions will be destroyed and the supervisory research committee will only review transcripts devoid of any identifying information during analysis. Consent forms and audio tapes will be secured in my private office. Data collected through this process will only be used to inform this study. All data from this study will be destroyed within three years of completion of this project.

Sharing of Findings: It is anticipated that the results of this study will be shared with others in the following ways: This study will be the topic of a thesis and will be available once completed through the University of Victoria library. A written summary report will be made available to you upon your request. I plan to publish findings in relevant practice journals so that information derived from this research can be shared with the health care community as a whole. Additionally, findings may be presented at professional conferences nationally and internationally.

Questions or Concerns: You may contact any of the individuals listed earlier to discuss this study. Ethical approval for this study has been granted by the University of Victoria Human Research Ethics Committee and the University of Manitoba Education / Nursing Research Ethics Board. You may verify the ethical approval of this study, or raise any concerns you may have, by contacting the Human Research Ethics Office at the University of Victoria (250-472-4545) or ethics@uvic.ca; or by contacting the Education/Nursing Research Ethics Board at the University of Manitoba (204-474-7122) or margaret_bowman@umanitoba.ca.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions of their legal and professional responsibilities. You are free to withdraw from the study at any time and / or refrain from answering any questions you prefer to omit, without prejudice or consequence. Our continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Name of Participant

Signature

Date

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

Please provide a means (below) to contact you if you would like to receive a written summary report of research findings upon completion of the study.

Phone:

Email or mailing address:

Appendix E

Sample Interview Questions to Initiate Discussion

Questions to explore what palliative care looks like / feels like in practice:

What do you think of when you think about palliative care?

Can you tell me of a time you have cared for a person that you have thought of as palliative?

- What was this like?
- How did you come to know that care was palliative?

Are there ever times that it is difficult to know when or how treatment goals should shift from curative to palliative?

- How does it feel for you when these goals change?
- Does this change what you do or how you do it?
- If so, How?

Questions to explore how palliative care is experienced as part of a team:

What is it like to provide palliative care as part of the team you work with?

- What do you feel your role should be?
- Do you feel this is the way others may view your role?

What part do you play when treatment goals shift from curative to palliative care?

- How is this similar or different than those you work with?

Questions to explore what facilitates or hinders the care nurses want to provide:

In your experience, what things make it easier for you to provide palliative care?

Are there things that make it difficult to give the care you want to give?

Has there ever been a time that you felt unable to provide the care you wanted to?

- What was this like?

Has there been a time that you feel care went exceptionally well?

- What made things work so smoothly?

In an ideal world, what would palliative care look like for people receiving treatment for advanced cancer?

Appendix F

Demographic Context

** Participants were asked to complete demographic collection form following interview*

ID # _____ Date: _____

1. Age:
What was your age on your last birthday? _____
2. Gender:
Male _____
Female _____
3. Years of experience as a nurse _____
4. Years worked in an outpatient oncology setting _____
5. Years worked in the following roles:
Coordinating care as a primary clinic nurse _____
Administering treatment and supportive therapy _____
Both _____
6. Most recent level of nursing education completed (please check one)
 - a) Registered Nursing Diploma _____
 - b) Post-Diploma Degree in Nursing _____
 - c) Baccalaureate Degree in Nursing _____
 - d) Master Degree in Nursing _____
7. Have you completed a post-basic / specialized palliative care course or training (e.g. Canadian Nursing Association certification in palliative care)?
Yes _____ No _____
8. Have you completed a post-basic / specialized oncology course or training (e.g. Canadian Nursing Association certification in oncology)?
Yes _____ No _____
9. Please share any other professional experience you may have had in oncology or palliative care
