THE GENDERED EXPERIENCES OF NURSES IN UNDERSTANDING HOPE IN

PALLIATIVE CARE

by

Gudlaug Einarsdottir

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ABSTRACT

This feminist phenomenological study explored the gendered experiences of nurses in understanding hope in palliative care. Six nurses from a palliative care unit in southern Ontario were purposely recruited for this study. The purpose was to acquire a deeper understanding of and find meaning in the experiential human condition of hope, as understood in the context of palliation. Four themes emerged: The Embodiment of Human Caring: Attending the Physical Body During Palliative Admission; Coming to Know in the Nurse's Engagement of Hope in Palliation; Stereotypes and Generalizations of Gender and Caring: Moving Beyond our Historical Legacy; From Empathy to Burnout and Back: Cultivating Self-Care Practices to Heal the Palliative Nurse. The study findings will potentially inform the education of healthcare providers working in palliative care, as well as those training in undergraduate, graduate, post-graduate and continuing education, particularly when understood in the broader context of evidence related to palliative care.

LIST OF ABBREVIATIONS USED

BCCEWH   British Columbia Centre of Excellence for Women's Health

CHPCA   Canadian Hospice Palliative Care Association

SRHC   Southlake Regional Health Centre

CIHI   Canadian Institute for Health Information

REB   Research Ethics Board

NCSBN   National Council of State Boards of Nursing

CNA   Canadian Nurses Association

RNAO   Registered Nurses' Association of Ontario

CPCP   Care for the Professional Caregiver Program

ACKNOWLEDGEMENTS

Chapter I   Introduction

Watching a peaceful death of a human being reminds us of a falling star; one of a million lights in a vast sky that flares up for a brief moment only to disappear into the endless night forever (Kübler-Ross, 1997, pg. 246).

According to Woelk (2008), the aim of palliative end of life care is to increase patients' quality of life as they move towards death. Woelk identifies the concept of hope as an essential part of quality of life and a crucial component of the human capacity to respond to adversity. Every patient has the right to be hopeful, and every healthcare provider has an obligation to support patients in their vision of hope (Duggleby and Wright, 2007). This makes studies in the area of palliation and hope important, not only for patients but for all nurses and primary care providers who work with palliative care populations and their families.

Palliative care is a global public health issue, as millions of people worldwide suffer from life-threatening diseases (Sepúlveda, Marlin, and Yoshida, 2002). In North America most people die in hospital thus, the need for palliative care emerges within almost every field of nursing practice and should always be centered on the personal needs of each client and his/her family (World Health Organization, 2002). Despite the global importance of palliative care and the relevance of hope within the field, there remains a lack of evidence in the field that examines the potential impact of gender on the experiences of health care providers, specifically nurses in their provision of end of life care. Insofar as nursing has been a gendered profession, often reduced historically to women's work (Egenes, 2012), understanding how gender has influenced the practices of palliative care nurses and their understanding of hope may offer us new insights for

optimizing care—specifically within current health care institutions and the practices of palliation.

Purpose And Research Questions

The purpose of this research was to acquire a deeper understanding of, and find meaning in the experiential human condition of hope, as understood from the gendered experiences of nurses in palliative care. It is anticipated that the results from this inquiry will potentially inform the education of healthcare providers working in palliative care, including practicing nurses, physicians, as well as those training in undergraduate, graduate, post-graduate and continuing education, particularly when understood in relation to the larger body of literature on palliation and hope. A deeper understanding of how dying individuals experience hope can also be utilized by healthcare providers in implementing strategies that both promote and maintain hope with patients in their care. This in turn may assist in achieving the foremost goal of palliative care: increasing quality of life and/or promoting a peaceful death (Duggleby and Wright, 2007; Kylmä, Duggleby, Cooper and Molander, 2009; Woelk, 2008).

The questions that guided this study included the following:

1. *What is the experience of nurses in understanding hope in the provision of palliative care*?

2. *What do nurses in palliative care consider supportive in maintaining hope in providing care?*

3. *What do nurses in palliative care consider challenging in maintaining hope when providing care*?

4. *To what extent do nurses consider gender influences their provision of care (or not), and, in particular, their understanding of the concept of hope?*

Reflexivity

For as long as I can remember, I have known I wanted to be a nurse, yet I never viewed nursing as women's work. My cousin was one of Iceland's first male nurses, and in Iceland, nursing has generally been viewed as a respectable and gender-neutral profession. I appreciate, however, that my former view on nursing as it relates to gender was slightly different because of my Icelandic upbringing and background.

I grew up listening to stories about the strong Viking women that settled my country in AD 874 (Palsson, 2007). Stories detailed how these Valkyries functioned on par with their male partners in the harsh new land they had just settled as it was ordered and practiced by the Norse Gods (Anderson and Swenson, 2001). Later, after being forced into Christianity, Icelandic women found themselves objectified by the Catholic Church as the lesser sex, to be ruled over by their male relatives and later husbands (Palsson, 2007). With spirits not easily broken, the Icelandic Sagas tell tales of fierce women and girls who fought this oppression - some were revered as heroines while others were convicted of witchcraft and drowned (Bryan, 2011; Vidar, 1997).

On June 5th, 1885, Briet Bjarnhedinsdóttir (1856–1940) wrote an article under the heading "A Few Words Regarding the Education and Rights of Women" (Gudmundsson, 2012, p.42). Today her article is credited as the catalyst for the beginning of public and political change regarding women's rights in Iceland. In 1894, Bjarnhedinsdottir founded the Women's Association, and later in 1907, she founded the first feminist political movement, The Icelandic Woman's Movement. Reflective of these changes, on

November 18ᵗʰ 1919, six nurse leaders came together and founded the Icelandic Nurses Association, a professional organization dedicated to the development of nursing education and training (Felag Islenskra Hjukrunarfraedinga, 2012).

It should be noted that my upbringing and cultural background may differ in many ways from my Canadian colleagues. My historical legacy shaped me, not only as a person, but also my identity as a woman, mother, and a nurse. I am a strong, independent, Icelandic woman, mother of three daughters and grandmother to two granddaughters. I am also fiercely proud to be a member of the nursing profession. Providing hope centered nursing care to patients facing death has filled me with a sense of higher purpose and inspired me to strive for improving aspects of my life. I was curious to uncover a possible link between this commitment to care and my gender. Therefore, my intent was to discover potential ways in which nurses gendered experiences shaped their perspectives of hope and the care they provided the dying patient. Historically and universally, nursing has been a gendered profession with a positioning of women's work, and as such, devalued. As the targeted study site was exclusive to female nurses (there were no men nurses employed on the targeted unit), recruiting women nurses using a feminist and phenomenological methodology was well suited to the study.

I will always remember my first experience with the death of a patient. The memory is vivid not because I was there and was able to experience her passing as a student nurse, but because of the matter-of-fact attitudes from my colleagues and the bothersome language they used to describe this woman dying. "She has expired" was exclaimed by my nursing preceptor as she finished checking for a vital sign. I felt saddened by the way the patient was being referred to, and the clinical atmosphere that

surrounded her death. I felt there was no respect, no dignity, and no love. This profoundly affected me in ways I couldn't articulate at the time but lingers still in my mind to this day.

As a result of my own experiences, from the onset of my career in palliative care, it has been a personal mission to encourage advances in the holistic care of patients, their families, and the nurses providing this specialized care. I have found that hope is a word not frequently used by healthcare providers when colleagues from other disciplines discuss a patient receiving palliative care. I believe my own gendered experience as a nurse as it relates to palliative care, has made me more acutely aware of how the ambiguity of my own embodiment as a woman affects how I perceive the importance of this topic. I have found that despite a level of intrigue in palliative care, fear often sways student nurses of both genders away from such placement opportunities. It was postulated by Zimmerman (2007) that this position may be reflective of our technologically advanced society having de-normalized death and the corollary perspective that death should be avoided at all costs. A change in this attitude does occur, however, once nurses come to realize the uniqueness of the nurse-client relationship and the recognition of how much impact care really makes. Unfortunately, care and other hope-promoting skills are not frequently fostered in nursing school curricula (White, Coyne, & White, 2012).

Hope is a term that is extremely applicable for the vulnerable populations nurses attend. As the great Greek poet Theocritus (1950) stated so memorably "*While there's life there's hope, and only the dead have none" (p. 37).* Those of us who have experienced the heartache of having to visit a loved-one on a palliative care unit are acutely aware of the impact the palliative nurse can have. A nurse's attitude, demeanour, stance, and gaze,

can greatly influence the end-of-life experience for a patient and her/his family in both positive and negative ways. Goldberg (2005) found the introductory moments of care during the intimacy of birthing were essential to establish a relationship with a woman and family; setting the stage for future health care encounters. Her research has relevance to palliative care and the vital role of the nurse in these introductory moments of that intimate relationship. An Oncologist colleague of mine once told me that he referred to this intimate tenderness of the nurse-patient relationship as the "Voodoo of Nursing" - a secret, treasured ingredient that is essential to establish a trusting relationship, yet unobtainable by many.

The intimacy of death is well articulated in the published memoirs of the nurse-midwife Jennifer Worth (1935-2011). In her final volume (2010), Worth reflects on how death can sometimes be a welcomed friend. "Death comes for us all and to show reverence in the face of death is the humility of acceptance" (p. 8). She reminisces about being witness to her grandfather's death as she states.

> In the last hours of life something mysterious happens, which can best be described as a veil being drawn. The dying person looks the same but is not the same. Afterwards, I wanted to lay out his body myself, as I had been taught in my first year of training. I prepared his body and put a shroud on him, in readiness for his last journey to his grave (p.15).

In the context of this study, my aim was to discover what front-line palliative nurses were experiencing while providing care for patients in palliation. How did they relate their care? Were they intentionally providing hope-promoting care? What resulted

if they did not incorporate hope in their care? Did they value hope as an important component in their everyday care? How did the nurses own gendered experiences impact the way they viewed themselves as care providers? Did they believe hope was viewed differently by women care providers? Moreover, if so, did that belief translate back to the way the nurses approached patients, their families and/or their engagement with other health care providers, including physicians?

As a graduate nurse from another country, I was worried that I would have difficulties gaining access to my study population here in Canada. In Reykjavik, Iceland, I previously practiced within the Oncology and the Palliative Care setting. This included direct patient care and the initiation of a clinical care pathway aimed at nursing the terminally ill at end of life. In this regard, I reserved the option to undertake this research in Reykjavik, Iceland if undue obstacles in accessibility to palliative care nurses here in Canada was encountered.

Review Of The Literature

I started out reviewing numerous research articles on the phenomena of hope and palliative care in order to gain insight as to where my own research question fitted within existing literature and to determine the significance of my own questions. I also wanted to explore the philosophical underpinnings and the methodology of choice that has guided previous research on the concept of hope and whether or not they aligned with my own philosophical beliefs. The literature is sorely lacking studies where the topic of hope is aligned with the notion of gender. History has portrayed nurses as handmaidens, far removed from the independent health care professionals of modern times (Egenes, 2012;

Pike, 2001). In their article *An End to Angels*, Gordon and Nelson (2005) maintain that the historical stereotypical image of the virtuous nurse trivialized nursing as a profession, reducing the role to that of self-sacrificing and devout female angels. Hence, I wanted to address this by looking closer at the origins of this interpretation.

There is an irrefutable link between the progression of nursing as a reputable profession and the struggles of women activists fighting for women's rights (Manojlovich, 2007; Clark, 1986). The question of how gender affects nurses' experience of hope for their patients, and the care they provide for both patients and families was the focus of this study. In what follows the relevant literature is explored in relation to the phenomena of interest: The gendered experiences of nurses in understanding hope in the provision of palliative care.

Hope

According to existing literature on the concept of hope, having hope and living with hope each day regardless of known impending death, is essential in maintaining quality of life and is also a vital part of the human capacity to respond to adversity (Woelk, 2008). Experts who have studied hope claim that while hope may help ease you of overwhelming doubts and fears, it is not denial. Rather, hope is being honest with yourself about your situation in life while still looking forward to possible positive outcomes in your future (Duggleby and Wright, 2007, 2009; Kylmä, Duggleby, Cooper and Molander, 2009; Larkin, 2010).

Denial was identified by Kubler-Ross (1969) as the first stage of grief. It's the psyches' foremost coping mechanism, an instant buffer between unbearable truths and the vulnerable self. Kubler-Ross identified five stages of grief that a person goes through

in a non-linear order: denial, anger, bargaining, depression and finally acceptance. In her book *On Death and Dying,* she further argues that hope never leaves the person going through the grief process "The one thing that usually persists through all these stages is hope" (Kubler-Ross, 1969, p. 126).

Findings from a Swedish grounded theory study identified social and psychological processes that cancer patients receiving palliative home care used to keep their hope alive (Olsson, Östlund, Strang, Grassman and Friedrichse, 2010). The sample of eleven participants was purposely chosen, and data was collected from participants in their home or in the palliative care unit through two in-depth interviews that were spaced six weeks apart. Additionally, seven participants were given diaries containing reflective questions regarding their spirits, hope, and coping. These participants were asked to write in the diaries when they felt that their hope had changed. A general theme in the data was discovered; "the responsibility for maintaining hope was theirs alone" (p. 608). Two processes cancer patients used to maintain hope when facing death emerged from the data analysis: maintaining life and preparing for death. The dual focus was personified in patients' striving to live as "normal" a life as possible (including being involved in daily activities with friends and family) while also preparing for death. –Preparing for death included; resolving old conflicts, saying goodbye to people they cared about, making funeral arrangements and put their finances in order. These findings give the reader insight into the parallel processes palliative patients are able to utilize in order to retain hope. This further punctuates how imperative it is for healthcare providers to recognize the influence they can have on their patients' sense of hope and quality of life (Olsson et al., 2010).

Sand, Olsson, and Strang (2009) conducted a study on the coping strategies of non-religious cancer patients in a palliative care program in Sweden using a hermeneutic interpretative method. –Non-religious Scandinavians don't believe in organized religion but are very spiritual at heart and don't refer to themselves as atheists (Lundmark, 2006). The belief in some type of afterlife is common, and they do practice most Christian traditions aside from attending church regularly (Lundmark, 2006; Strang, Strang, and Ternestedt, 2002). The objective of the research was to understand what receiving a terminal cancer diagnosis had meant for the patients and to identify the strategies these self-proclaimed non-religious patients used to cope with their situation. The authors rationalized their approach as allowing for a deeper understanding of the meaning of the patient's experiences, and the implicit issues that are expressed yet sometimes hidden. The study sample of twenty palliative patients was purposely chosen with intentional maximum differences in demographics. In-depth, semi-structured interviews using dialogical validation (to enhance trustworthiness) were used. The authors' findings concluded that strong relationships, hope in normalcy, being pain-free and strong beliefs in life after death were the prime factors utilized by non-religious Swedes to cope with impending death (Sand, 2009).

An earlier Swedish study by Benzein and Saveman (1998) also found that using a hermeneutic interpretive methodology was best suited to explore nurses' perception of hope amongst palliative care cancer patients. This study differed from the previous study in that the focus was on the nurses' view of hope and what it meant to them as it related to their patients. The sample of nine women nurses with an average of ten years of work in cancer care was purposely chosen by the nurse administrator at the palliative care unit.

The nurses were interviewed with open-ended questions pertaining to hope, aimed at helping them reflect on the phenomenon and what fostered or reduced patients' hope. Findings from the study indicated that nurses expressed hope as a realistic, future-oriented phenomenon that portrayed the cancer patients' inner strength and energy despite knowledge that death was fairly imminent.

In 2010, Mok and colleagues used Husserl's phenomenological approach when conducting a descriptive study in Hong Kong. The study examined how Chinese cancer patients perceived hope. A convenience sample of 17 advanced cancer patients from the palliative care unit of a local hospital was used with the following inclusion criteria: twenty-one years or older, terminally ill and mentally alert. Interview data indicated that hope, as it is experienced by the Chinese cancer patients, consisted of five components: living a normal life, social support, acceptance and preparation for death, concern for the well-being of others, and actively giving away control. The researchers concluded that as the Chinese culture sees value in giving up control, healthcare professionals can foster hope in their patients but need to be aware of cultural differences, including those related to the concept of hope.

In order to gain a better understanding of the various ways hope is referred to in palliative care practice, Olson and Colleagues (2014) conducted semi-structured interviews with 64 healthcare professionals from the Netherlands and Canada. Furthermore, practice observations were used to confirm interview analysis. Findings concluded that healthcare professionals in both countries use plethora of metaphors to relay the fundamental meaning of hope. Participants described hope as feelings of security or safety; hope was a source of strength, hope was to live in harmony and lastly

having a positive perspective implied hope. The researchers hope that these findings will increase awareness of how various metaphors are being utilized to convey hope which will ultimately improve communication around hope in palliative settings.

Duggleby and Wright are two Canadian nurse researchers who have done extensive research on the concept of hope. In 2007, during a palliative conference in Western Canada, they recruited 113 professional caregivers attending a hope workshop, to participate in a mixed method study on how professionals describe hope in palliative care. Participants completed a demographic questionnaire, the Herth Hope Index, and an open-ended hope survey. Findings revealed that caregiver hope was influenced by various factors including; having adequate time and resources to spend with patient and family, being able to establish supportive relationships with colleagues and patients, being able to control patient's symptoms adequately, which lead to feelings of accomplishments, and connecting with their own spirituality. Participants all discussed how their own notion of *hope* was instrumental in being able to pay it forward and instil hope in their patients (Duggleby and Wright, 2007).

In 2009, using a grounded theory approach, the authors identified how elderly palliative cancer patients in rural Canada experience hope. Based on a sample of ten participants, their results showed that elderly palliative care patients want to live with day-to-day hope while acknowledging that hope transforms or changes throughout their illness. The hope for more time became a hope for a more quality time to spend with loved ones. Finally, there was hope for a peaceful and painless death (Duggleby and Wright, 2009)

Richardson, MacLeod and Kent (2012) discussed how nurses can connect with patients on a deeper emotional level during end of life care by using a Steinian approach that utilizes empathy to reduce fear and hopelessness. They point out that a perception of another's experience acknowledges what the person is experiencing without them having to live the experience themselves. It is this standing side-by-side with the dying patient, being able to connect with and perceive his/her unique emotions as separate people that clearly demonstrates the nurses' empathy. At the same time, Steinian empathy requires nurses to be cognitively aware of own emotions and distance through self-reflection, while acknowledging their patients situational reality (2012).

Gendered Approach

Research shows that low quality of life and intractable symptoms are factors that intensify existential distress and hopelessness in palliative care patients (Krikorian, Limonero, and Mate, 2012; Mystakidou et al., 2008). In her paper on gender and cancer, Moynihan (2002) addresses the importance of incorporating a gendered relational approach to physical and psychosocial care. She emphasizes the need for further research on gendered disease experiences and argues for abolishing the stereotypical "male vs. female" gendered expectations of disease experiences in the context of the provision of care (Moynihan, 2002).

Research to date shows interest in advancing knowledge in relation to how gender shapes patient experiences (Ersek, Smith, Cannuscio, Richardson & Moore, 2013; Fillingim, King, Ribeiro-Dasilva, Rahim-Williams & Riley, 2009; Kamath & O'Connor, 2011). In 2013, Ersek and colleagues performed a nationwide study with female and male US veterans on the quality of end-of-life care. Although only 2.1% of the total study

sample represented women, the researchers reported no significant gender disparities related to overall satisfaction with the quality of care (Ersek et al., 2013). The British Columbia Centre of Excellence for Women's Health (BCCEWH), has published guidelines for the development of nationally accepted policy and regulation for palliative care. The guidelines explicitly argue the need for a gender-based analysis to identify gender-specific needs for palliative care patients (BCCEWH, 2007).

Palliative Care

According to the Canadian Hospice Palliative Care Association [CHPCA] (2013), the word palliative or /pal.liˈaː.tus/ has its origins in Latin and means to cloak, shield or protect and today is used in reference to the management of palliative symptoms. Palliative care ideology is intertwined with the early hospice philosophy of hospitality for the sick and injured traveler that originated in the 4th century A.D during the Christian crusades (CHPCA, 2013). Women have historically been the ones to nurse the sick and injured (Egenes, 2012). In the 19th century, hospices were run by religious sects and nursing care provided by women or monks called by religious beliefs to nursing (CHPCA, 2013). Nurse, and later physician, Cicely Saunders, instrumented what would later become known as the modernization of hospice and palliative care (Clark, 2007). It can be said that Dr. Saunders' approach to care of the terminally ill patient comes from a feminist perspective. She refused to separate the illness of the body from the suffering soul and was a pioneer in the idea to care holistically for the patient, physically, emotionally and psychosocially (Clark, 2007). Cicely Saunders founded St. Christopher's Hospice "the world's first modern hospice" in 1967 London, UK. St. Christopher's Hospice was the first of many hospices established around the world; their teachings and

practices transformed our modern day philosophy of hospice and palliative care (Clark, 2007; CHPCA, 2013).

Gender And Nursing

Henly and Moss (2007) identify that from earliest times, nursing as an act of caring has been assigned to women. Many ancient societies equivocated the attributes of women as nurturers and carers of children to a natural assignment to caring for sick persons (Henly and Moss, 2007). Through the Middle Ages, nursing was tightly linked to religion; women that sought nursing as a profession were drawn to the profession by a spiritual yearning to become closer to God through self-sacrifice (Egenes, 2012).

As nursing progressed in Europe, the role became associated with more education. Christian women were appointed nurses or "Deaconesses" by their Bishop. These women visited and cared for the affluent sick in their homes (Egenes, 2012). The Hotel Dieu in Paris (a hospital founded in 651 A.D. by the Bishop of Paris) was run by the Augustinian Sisterhood; St. Vincent de Paul's Hospital of St.Lazarre was staffed by a group of women known as the "Daughters of Charity." These women were vowed to the mercy of all the sick, and provided more compassionate and holistic care to their patients than was known in the rest of Europe at the time (Watt, 2006).

For example, at the same time, nurses in Britain were recruited from the lowest ranking, disgraced by society's norms and otherwise labelled, desperate women. Without affiliation and support from the church, no prestige or respect was given to the profession (Egenes, 2012). No formal education was available in these early days of nursing and required nursing skills were gleaned through trial and error (Watt, 2006).

A Nurse: The Angelic Lady With The Lamp

During Victorian times in Britain, young ladies from noble families were socialized to become adequate in the arts of social conversion, needlework, art, music and other accepted activities (Holliday and Parker, 1997). As a young highly intelligent woman, Florence Nightingale had aspirations that far exceeded society's "accepted" normal behaviour expected of young ladies of the time. Her refusal to obey the norms and eventual travel to attend nursing training in Germany resulted in her being ostracized by her mother and sister as well as being rejected by the Victorian high society (Holliday and Parker, 1997).

Nightingale stubbornly fought hard against her family and upper-class society to succeed in her ambition for herself. Her feminist characteristics' are best described through her aspiration for her chosen profession. According to Williams (2008), Nightingale believed she had a calling from God. Although quite unsure what she was meant to do, she concluded that her calling was nursing the sick and contributing to the betterment of others through reforming health practices. She refused to allow social status and gender role expectations to hinder achievement of her goal (Williams, 2008). Nightingale didn't like the word "nursing" for this profession. In her book *Notes on Nursing*, she stated, "I use the word nursing for want of a better one" (Nightingale, 1860, p. 2).

During the Crimean war, Nightingale gained the nickname "the lady with the lamp" from the soldiers she cared for (Cook, 1913). The nickname became forever associated with her after the British poet Henry W. Longfellow published his poem,

"Santa Filomena" (Patron Saint of the Sick). The tenth verse immortalizes Nightingale as the noble, good and angelic lady with the lamp.

…"A Lady with a Lamp shall stand

In the great history of the land,

A noble type of good,

Heroic womanhood."… (Longfellow, 1902, p.285).

Publicly the image portrayed of Nightingale is one of an ever gentle, kind, dainty female with a cap (Holliday and Parker, 1997). This in no way gives justice to the effective, hardworking, linguistic scientist that she was. Being methodical, assertive, and resourceful, she quickly turned to her passion for statistics when problem-solving. She understood that data needed to be accumulated, organized and presented as evidence in order for her to assert the changes in healthcare she strived for (Dossey, 2010; Gladfelter, 2007).

As noted by Smith (1982), from her notes and rigorous documentation, she developed a questionnaire that pushed forward the Indian Sanitary Reform. With data collected from the questionnaire, she acquired evidence needed to gain political support and institute changes to improve the health of British military personnel in India (Hays, 1989). Nightingale was frustrated with Victorian women's lack of knowledge about their own bodies, lack of formal education, lack of general interest in science and the workings of the otherwise "man's" world (Holliday and Parker, 1997). She worked diligently towards raising the status of hospital nurses and demanded absolute obedience from nurses working under her leadership (Holliday and Parker).

Masculinity And Nursing

As noted above, nursing has been assigned to women from earliest times (Egenes, 2012; Henly and Moss, 2007; Watt, 2006). Contradictory to these aforementioned researchers, Evans (2004) points out that men have been an integral part of the caring profession alongside women from the start of time. She states that with the introduction of the modern day nursing model introduced by Florence Nightingale, men were driven out of the nursing profession and into the more socially acceptable gendered role of the physician.

Statistics speak to the evolution of modern day perspective in gender equality in context of men and the nursing profession (Evans, 2004). However, this is a slow progression; in 1973, men represented only two percent of the entire nursing force in Canada, and according to the Canadian Institute for Health Information (CIHI, 2011) almost forty years later, the total percentage of men in nursing is still under seven percent. It is curious that although men represent only a small number of total nurses in Canada, they hold over five percent of all managerial and administrative roles. A questionable trend due to the fact only three percent of women nurses occupy similar roles (CIHI, 2011; Evans, 2004). This disparity isn't confined to administrative roles as according to statistics, very few men choose a career in maternal, community or pediatric nursing -opting for a career in specializations considered more congruent with masculine traits. Williams (1995) postulates that due to cultural and social stereotypes about masculinity, men nurses are being pressured to pursue a career within specialties that are socially acceptable for men in patriarchal culture, .i.e. psychiatry, emergency care, intensive care, anesthesia and administration (Evans, 2004; Williams, 1995). Differences

are also noted in earning potentials, in a report by the U.S. Census Bureau published in 2013, it notes that gender difference is still prevalent among nurses in the U.S. In comparing wages among men and women nurses in the same role, the bureau reported that men earned considerably higher than a women nurses in the same nursing position (U.S. Census Bureau, 2013).

In summary, despite a growing literature on hope and gendered experiences of patients, the gendered experiences of nurses providing hope in palliative care has not been adequately understood. Nursing and other caring professions, despite many compelling advances, continues in many ways to be viewed as "women's work," thus resulting in the disempowerment of nurses, specifically those who are women (Manojlovich, 2007). As this study examined the gendered experiences of palliative care nurses and their understanding of hope, it was fitting to utilize a phenomenological feminist framework.

Chapter II   Methodology

As I sought a deeper understanding of the world in which nurses providing palliative care live, and their gendered understanding of the concept of hope, I turned to feminist phenomenology as an experiential framework to guide my study. Phenomenology as a methodology is essentially the study of the lived experience or the life world; it gives primacy to experiential data (Benner, 1984; Giorgi, 1985; Goldberg, 2002, 2003, 2005, 2008; Goldberg, Ryan & Sawchyn, 2009; Merleau-Ponty, 1962; Van der Zalm and Bergum, 2000, p. 212; van Manen, 1997, p. 62). In culling a deeper understanding of and find meaning in the gendered experience of hope during palliation, feminist phenomenology seemed the obvious tool for researching the gendered experience of hope for nurses providing palliative care, in order to promote more comprehensive understanding and meaning in the context of their clinical care.

The fundamental philosophical orientation of phenomenology is viewed by nurse researchers and feminist scholars as particularly relevant for nursing (Benner, 1984; Goldberg, 2002, 2003, 2005, 2008). The identified aim of the orientation is in the discovery of lived experiences of another person and how it relates to the world they live in, including embodiment, beliefs and values in their social context (Merleau Ponty, 1962). Benner and other phenomenological researchers find this approach particularly beneficial to nursing practice where the intent is to improve or inform practice by ways of understanding the phenomena the participant has experienced (Benner, 1984; Giorgi, 1985, 2009; Goldberg, 2002, 2003, 2005, 2008; Goldberg et al., 2009; Van Manen, 1997).

Existential Phenomenology And Maurice Merleau-Ponty

The French philosopher Maurice Merleau-Ponty was born in 1908 and died in 1961 at the age of 53. Impacted by the turmoil of his time, the violence he witnessed during WWII and the struggles that society endured in the aftermath of the war, he was heavily influenced by the ideologies of Karl Marx, which preached social equality and the obliteration of the class system (Dillon, 1991). Merleau-Ponty's philosophy is rooted in Husserl's school of thought as he began his career studying the German philosophers (Earle, 2010).That said, according to Moran (2000), Merleau-Ponty's own understanding of the lived world and what it meant to be in the world, distanced him from Husserl's ideology of empiricism and phenomenological reduction, insofar that he believed this would lead to a distorted account of experience. Accordingly, Merleau-Ponty's philosophy is largely grounded within existential phenomenology, thus viewing the body as interconnected, with an inseparable connection of mind and body (Goldberg et al., 2009).

According to Merleau-Ponty (1962), the world is experienced as embodied – an inseparable integration of the lived body situated within the world. One cannot live without the other. This notion of embodiment is what separates Merleau-Ponty from the Cartesian school of philosophy— as he rejected the fundamental Cartesian dualistic beliefs regarding separation of body and mind (Goldberg, 2002). The world and how the embodied person fits within it, is experienced by individuals differently. Although worldviews can be communicated, perceptions of how individuals perceive their worlds and their bodies within it can only be shared through understanding of their mutual perception (Giorgi, 1985; Merleau-Ponty, 1962; Goldberg, 2002). Gadow, (1989)

described the most compelling explanation of embodiment; the notion of re-embodiment for nurses through the most vulnerable patients, "the silent patient". This would entail that the "the nurse is speaking with the patient's voice" (p. 541).

Phenomenology using the philosophical underpinnings of existential philosophy through Merleau-Ponty fitted well with this study. Insofar as palliative care further endeavours to understand persons at their most vulnerable during their bodily experiences, Merleau-Ponty's notion of embodiment provides grounding for understanding nursing work within palliative care. However, to further understand palliative work and the notion of hope that is gendered, a feminist framework was a necessity, as Merleau-Ponty has been criticized for articulating a male conceptualization of bodies (Goldberg, 2005; Grosz, 1994; Olkowski and Weiss, 2010; Ryan, Goldberg, and Evans, 2010).

Feminist Phenomenology

This study revolved around women's experiences, specifically how a woman nurse experiences hope while providing care for a dying individual in the context of institutional care. Although agreeing with Merleau-Ponty's philosophy on the embodiment of the person, feminist phenomenologists have addressed the masculine and patriarchal underpinnings of his work (Goldberg, 2002, 2005; Goldberg et al., 2009; Moi, 1999; Olkowski and Weiss, 2010; Ryan et al., 2010). Merleau-Ponty's approach is that the mind-body connection is inseparable, and as he takes the male as the default position from which to examine human existence and philosophy, the female is relegated to "other." Moi (1999) pointed out that this is in fact what happens in society as well.De Beauvoir's feminist theory (1949) claimed that the whole body is fundamental to

understanding the life of an individual. The world is lived and, subjectivity is developed through one's body, as the body represents both possibilities and limitations. Therefore, all changes to the body must be viewed with a gender perspective (de Beauvoir, 1949). Patricia Young (2008) remarked in her paper that research undertaken from a feminist perspective heightens the awareness of collaborative, egalitarian values within the science of nursing education (p. 97). In her original essay "Throwing Like a Girl", Iris Young (1980) argued that one isn't born with preconception of one's gender and knowledge of how to act accordingly. Notable in her writings on spatiality is her observation on gendered movements and demeanours. She claimed that girls function within a set parameter where their functional space is small and limited. In a follow-up essay "Throwing Like a Girl: Twenty Years Later" (1998), Young acknowledged that to some degree- cultural progression has taken place resulting in greater acceptance of unrestricted bodily expression by girls and women (p. 288).

Iris Young (1980) further argued that *woman,* as a result of repetitive conditioning by what constitutes societies norm, is inherently confined in her lived spatiality. Conversely, nurses aim to formulate trusting engaging relationships with their patients and their families, where they emit professionalism and self-confidence as skilled providers of care (Goldberg, 2005). Bartky (1990) pointed to this inherent dualism, stating "feminine movement, gesture and posture must exhibit not only constriction but grace as well" (p. 67). Only by employing feminist theory did I discover the embodiment of the professional *nurse*, within the gendered body of the *woman.* I was keen to explore whether this was appreciated as individuation to be celebrated and nurtured, or constricting to the relational nature of the nurse-client relationship.

In the context of this study I observed the demeanour of palliative care nurses while working -how they walked, talked and carried themselves while engaging with other professionals, taking particular notice to attune to their manner and demeanour in their interactions when transfer of accountability occurs, and the developing relations with other members of their team.

Methods: Data Collection

Sampling

Qualitative inquiry sampling focuses on acquiring in-depth, information-rich data from a small number of participants (Giorgi, 2009; Patton, 2002). I employed purposeful sampling for the recruitment of participants for this study. Purposeful sampling is commonly used in qualitative research; it involves selecting research participants according to the needs of the study (Denzin and Lincoln, 2003; van Manen, 1997). In this regard, researchers choose participants who give a richness of information that is suitable for detailed research (Patton, 2002).The main objective for participant selection in a phenomenological study is ensuring that all participants have experienced the phenomena of interest (Giorgi, 2009, p. 3; van Manen, 1997).

The selection criteria for this study included palliative care nurses who had the ability to articulate their experiences in relation to the phenomena under investigation. According to Roberts and Priest (2006), the sample of participants is drawn from the population of interest which represents the study population at the time of the study. Purposely selecting participants with maximum variation in demographic background i.e. age and work experience, is essential as it provides a better sense of understanding into whether or not there is a possible shared component for all participants in regard to the

notion of hope in the context of providing care for terminally ill patients irrelevant of variations in prior experiences or demographics (Patton, 2002).

Sample Size

Englander (2012) stated that the researcher can interview her/his participants multiple times although she/he is not required to conduct follow-up interviews. The researcher should take cues from participants and direct/re-direct them toward the topic being described (Englander, 2012). In this view, he disagrees with the assumptions of Morse (2000) in which she articulates that in a phenomenological study, the researcher interviews each participant multiple times in order to gain insight into the phenomena of interest and add depth and richness to the data. Englander also pointed out that there is no predetermined fixed number of participants, and that a small number can be an advantage as it's the participants lived experience and how well the researcher is able to describe that experience that matters in a phenomenological research. He cites Giorgi (2009) in his assertion that a fixed sample size in qualitative research is basically irrelevant. Granted, he points out that in order to achieve the richness and depth of the experience he recommends at least three participants for a phenomenological study (p. 198).

He goes on to explain that this has less to do with the actual number itself or generality of the results; having only one or two participants can make it difficult for the researcher to acquire the deep understanding of the experience she/he seeks and can be overwhelming for the researcher. Additionally, it may even interfere with the researcher's ability to distance her/himself adequately from the participants (Giorgi, 2009). Sandelowski (1995) suggests that sample size for a phenomenological study is dependent upon the richness of the data collected from participants. However, she allots a certain

amount of pragmatism in that she argues a sample size of 5 can be sufficient when large amounts of in-depth data is obtained. Morse (2000) concurs with the notion that a greater amount of rich data may lend itself to fewer participants required. Reflective of Sandelowski's and Giorgi's recommendations, initially I recruited five participants for this study, however, in order to add depth and richness to the text one additional participant was invited to participate.

Recruitment Strategies

This study required approval from the Research Ethics Boards at Dalhousie University and Southlake Regional Health Centre (SRHC). I communicated with the Director of Medicine, the Palliative Care Team, and the Nursing Manager of the Palliative Care Unit at SRHC via e-mail and introduced them to the study. With collective approval from the aforementioned individuals and groups, they agreed to become key informants in the process of purposely selecting participants able to add richness and depth to this study. In addition to posting flyers around the unit, I hosted and invited the nurses to two *lunch and learn* that allowed for a more relaxed discussion regarding this study. At that time, I distributed additional flyers with relevant contact information (researcher contact telephone number and email).

Setting Context

Southlake Regional Health Centre (SRHC) has grown immensely over the past 30 years -from humble beginnings as a small York County hospital to the full-service Regional Health Centre it has become. Southlake accommodates 400 in-patients, has a very busy emergency department with over 90,000 visits per year, numerous outpatient clinics, as well it provides various advanced speciality services to over one million

residents in the York region. The nine-bed palliative care unit resides on the 6th floor as an ad-hoc unit to the larger 22-bed inpatient cancer care unit. Additionally the palliative team has access to six palliative beds located on the medical complex care unit on the third floor.

The palliative care unit is built in a circular fashion with its nursing station at the front and peaceful family room and a small kitchen at the back. All but two of the patient rooms are private rooms. Currently, SRHC is working on remodelling/upgrading the accommodations on the palliative care unit in order to better serve patients and their families. The physician-led interprofessional palliative care team consists of physicians, nurses, physical and occupational therapists, dietitian, spiritual care, social worker and volunteers.

Practice Observations

Following the conclusion of all participant interviews, I arranged with the Nurse Manager to schedule two 4-6 hour practice observational periods at the palliative care unit. Subsequently it was clearly articulated to the entire staff that my presence was strictly as an observer/researcher, as practice observation allowed for a deeper contextual understanding of the practice culture, rapport and support on the unit within the palliative care milieu. In accordance with Maggs-Rapport (2000), observation allows the researcher to add more depth and a deeper understanding of the practice environment the participant is experiencing. Context to the bigger picture was also ameliorated.

In-Depth Interviews

When the nurses had agreed to participate in the study and were willing to be interviewed, a meeting was scheduled at a date, time, and location of their convenience. As expected, most interviews took place at the nurses' homes, although any place of potential participants' choosing was accommodated within reason. The interviews were dialogical and conversational, thus promoted a relaxed environment (Broom, 2005; Goldberg, 2005). Each in-depth interview lasted approximately one hour and was digitally recorded. The semi-structure interview guide (Appendix E) included the questions guiding my study (p.4), in addition to probes, with the expectation that there would be a necessity to ask follow-up questions that came of the dialogue in order to provide clarity. A Dialogue focused and conversational framework for data collection is a fluid model, whereby there is an interaction between the interviewer and the nurse participant in an effort to acquire rich and meaningful data (Broom, 2005).

As discussed in Rubin and Rubin (2012), qualitative interviews allow the researcher to gain experiential knowledge and insight into a phenomena of interest from the perspectives of the people that have lived the phenomena. It's an in-depth inquiry, allowing the researcher a glimpse into the lived world of study participants (Rubin and Rubin, 2012).

Reflective Journaling

Throughout the study, I also kept a reflective journal to record my thoughts, feelings, observations and interpretations of each step of the study process. Keeping a reflective journal assisted me in making a connection between my own thoughts, feelings, and prior experiences, and that which I observed during interactions with study

participants (Benner, 1984; Ortlipp, 2008).Increasingly, qualitative research (particularly that which is situated within feminist and critical paradigms) uses reflective journaling in order to create transparency in the research process and show how the researcher's own experiences, culture, beliefs, and values have influenced her/his research. Consequently, it is important to use reflection to remain true to the phenomenon being investigated (Ortlipp, 2008).

Timeline

The duration of observational shifts, interviews and journal entries was six months. Concurrent and subsequent analysis and writing of all data collected took additional five months. Thus, final results from the study were available eleven months from the time of initial data collection.

Inclusion/Exclusion Criteria

The study sample consisted of six palliative care nurses that met the following inclusion criteria.

1- All participants were registered with the College of Nurses of Ontario.

2- All participants had at least three years' experience of palliative care. (*Having acquired higher level of proficiency will be reflected by a greater comprehension of the topic being studied*).

3- All participants were able to communicate in English coherently.

4- All participants were willing to discuss the phenomena of interest at length.

5- All participants signed an informed consent form prior to participating in the study.

Data Analysis

Data collection and analysis is an ongoing process and is not done in sequence despite appearing that way (Bassett, 2004). I brought a digital tape recorder to each interview as well as the interview guide (see Appendix E), demographic questionnaire (see Appendix C), and notebook. Within phenomenological analysis, the first step is to record what has been communicated in verbal and non-verbal form into a permanent written record (Cohen, Kahn, and Steeves, 2000). Thus, each audiotaped interview was transcribed verbatim immediately afterwards by a professional transcriber, and the data checked for accuracy by listening and comparing to the transcribed document. All data was read, reread and reflected on in relation to other data such as the researcher's own reflective journal, current feminist and palliative care literature, and supervisory/committee feedback. Throughout this process, and in accordance with feminist perspective, I focused on the phenomena being explored, empowering the nurses to share their stories and lending their voices to their unique experiences.

An inductive research method that involves grouping and drawing themes from the data gives the researcher a general feeling and insight into the lived experience of the phenomena being studied (Van Manen, 1997). According to Wojnar & Swanson (2007), comparing different data (e.g., interviews, observation and reflective journaling) will give researchers, a bigger overall perspective of the meaning of the experience for each participant. Merleau-Ponty (1962) stated that no one's perception of an experience can be shared completely, as the body-mind-world perception is perceived only by a specific individual, occupying that body, at a particular time and thus cannot be transferred or generalized. As in other phenomenological studies, the researcher is subjected to the lived

experience of an individual that is contextual to his/her previous history, socio-cultural context, values, and norms. Therefore, findings are not transferable between individuals (Annells, 1996). That said, there is application relevance ascribed to a study of this nature because there could be parallels in application of the experiences of the women in this specific population to other nurses on units that mirror the unit employed in this study.

In extracting significant statements pertaining to the phenomenon being studied, meanings were formulated into themes. Emergent themes that surfaced from all data collected from each participant were grouped together and reviewed again. Braun and Clarke (2006), identified that "A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set." (p.82). Themes were clustered and validated with the original text to identify experiences or meaning shared among all participants. Thematic analysis of all interview and textual data, as well as my own reflection notes, allowed me to explore the commonalities experienced by the women palliative nurses. I was completely transparent in this process, inviting the participants to read and comment on their transcripts and my interpretation of their data. From a feminist standpoint and within the context of providing gendered nursing care, I focused on unveiling the nurse's lived reality as it related to the physical understanding of her bodily world (corporeality), the existential non-linear experience of subjective rather than objective time (temporality), the dimension of space that is felt intuitively rather than understood as a tangible physical element (spatiality), and the relations and encounters with others that we invite to occupy or share our space (relationality). This multifaceted focus allowed me to interpret and

describe the data within the context of existential and feminist phenomenology in relation to the questions being asked.

Ethical Considerations

My study involved collecting very personal data from individuals and consequently, I as the researcher had to be aware of any and all ethical issues that might arise during the study and be able to assure the participants that their rights, values and needs were protected at all times throughout the course of the study (Creswell, 2007). Before I began my research journey, I received authorisation from the Director of Medicine at SRHC and sent a study proposal to the Dalhousie University Research Ethics Board for approval. No individuals were contacted regarding this study until authorization was obtained from all agencies involved.

All participants signed informed consents prior to participating in the study. Each participant was provided with a document that clearly articulated all pertinent information regarding the study; information was also discussed. Participants were advised that participation was completely voluntary and that they could withdraw from the study at any time; they were also be informed of their right to refuse to answer any question. I included information surrounding all data collection and storage of the data as well as the participants' right to see and discuss both their transcripts and my analysis of their data. Confidentiality was maintained for the participants by employing pseudonyms in place of actual names in all written records. All the data was and will be kept confidential. The audiotapes were kept in a locked cabinet, when not in use, in my home

office and were destroyed after they were transcribed. Original data will be kept in a locked location and destroyed five years after completion of the data analysis.

Conflict Of Interest

I have been a part-time employee at Southlake Regional Health Centre (SRHC) in Newmarket, Ontario since 2012. I was a part-time staff nurse on Cancer Care until 2013 when I took a part-time position as one of three Nurse Educators for the Medicine program. My focus is on Oncology; more specifically Chemotherapy and Biotherapy. - However, I have absolutely no authority, power or influence over the study participants that might conflict with the study. My role in this research was clearly articulated and completely set apart from my oncology employment duties.

Conclusion

In my work in palliative, end-of-life care, I have found that the common misconception amongst (non-palliative) healthcare providers when it comes to the notion of hope is that they expect patients to feel hopeless as a standard response to advanced terminal disease. This both surprised and saddened me because healthcare providers are in a unique position to influence their patients hope as a natural extension of their close relationship with them. They are able to foster, enhance, maintain and/or destroy a person's sense of hope through their attitudes, behaviours and ways of communication. The goals of this study were twofold: First, I aimed to understand the gendered experience of hope while providing palliative care; second, I sought to translate the findings into clinical practice, thus bridging the gap between research findings and clinical nursing practice. When viewed in the context of the larger body of evidence in

palliative care, the findings from this study may serve as the basis to change palliative

care education by having the potential to enhance the quality of life for the dying patient.

Chapter   III

The Embodiment Of Human Caring: Attending The Physical Body During

Palliative Admission

"When we are suddenly released from an acute absorbing bodily pain, our heart and

senses leap out in new freedom; we think even the noise of streets harmonious and are

ready to hug the tradesman who is wrapping up our change."

(George Eliot, 1902, p. 164).

Introduction

The cultivation of a caring relationship in palliative care begins with initial

admission to the unit by way of hospital transfer from another unit or by ambulance from

a patients' home. It is that crucial moment; that foremost instance when a nurse first

gazes upon her/his patient and embodies the potential to create a relationship that is, due

to its intimate nature, unlike all other relationships in care (Goldberg, 2005, 2008).

According to Watson (2009), to *care* is simply to *love*; to be genuinely concerned with

the wellbeing of others and be able to demonstrate unconditional kindness and

compassion towards another person. It requires a person to encompass a helping attitude,

and with an open heart, have a genuine desire to connect intimately with another human

being (Halldorsdottir, 1997; Larkin, 2010).

In what follows, this chapter will illuminate the theme entitled, *the embodiment of*

human caring: attending the physical body during palliative admission. This theme

specifically explored nurses' experiences in attending to the patients' bodily needs upon

admission to the palliative care unit. These experiential findings addressed how the

nurses cultivated this relationship with their patients in palliative care; the relevance of these relationships to understanding the suffering body; and the fundamental role nurses played in supporting patients' and families during palliation. Nurses often have to go against the institutional health care landscape pervasive with gendered, hierarchical and power dynamics (Goldberg, 2005; Larkin, 2009).

Initial Encounters: Experiences Of Bodies, Suffering, And Care In Palliation

Within the context of the research, nurse participants often suggested that initial encounters with patients were acuity focused; with their attention aimed at the *task* of relieving the acute suffering of the physical body. –It is relevant to recognize that each person embodies the world differently, all experience, perceive and interpret the life-world around them through their unique bodily experiences (Merleau-Ponty, 1962).

In accordance with Merleau-Ponty (1962), a person's perception of their environment and their relationship to others within this environment is experienced, understood and expressed through their body. Yet, for Merleau-Ponty, the mind and body are innately conjoined. This is relevant to the area of palliation and nursing, insofar as the experience and perception of suffering are not merely physiological, but rather, are understood as part of the spiritual, emotional and psychosocial dimensions (Merleau-Ponty, 1962; Olkowski and Weiss, 2010). One is thus innately aligned with the other in the life-world of human experience. This is consistent with the storied narratives of the nurses in the study; they concurred that one cannot address the whole of the body when one part of the body suffers. As with unbearable pain- addressing the *pain* supersedes all other care. Pain is one of the most feared symptoms at end of life, and unrelieved, it

causes undue distress for patient and families as well it can exacerbate any other symptom (Cassell, 2009; von Gunten, 2005).

The concept of *total pain* is frequently referred to in palliative care to describe the physical, emotional, social, and spiritual anguish as experienced by the dying patient. Cicely Saunders instigated the concept of *total pain* in 1959 when she stated "Much of our total pain experience is composed of our mental reaction" (p.1032). Since then the notion of total pain has grown and matured into what it is today, an acceptable term to use for a *body* in total physical and existential pain. As Chiara, one of the nurses in the study reminded us:

> For a newly admitted patient, you immediately have to address the acute symptom, and once that's under control and well managed, you can begin the process of getting to know the patient and his family. That sort of how you begin laying the building blocks of a trusting relationship.

One cannot practice holistic nursing care unless all parts that make up the person are at an optimal comfort level. Aria, one of the participants, pointed out that in palliative care "your patient is not just the person receiving palliation; rather you need to include in your care and observation the psychosocial wellbeing of the immediate family and close friends." Halldorsdottir (1997) has suggested, when the acuity of a particular situation warrants, nurses have to reorganize themselves and prioritize their care according to the immediate needs of the patient at the center of their care. Yet nurses must always be mindful of the needs of the family.

Similar to Halldorsdottir (1997), Angela, one of the nurse participants, commented on a patient regarding the following situation:

We had a patient that had come over from another unit who had just been made palliative and all that kind of stuff. And she was really breathless at the time and the family was really concerned because they weren't comfortable with how their mom was looking and feeling once in the bed. They were explained one thing when they were told what palliative care was all about, and now they weren't seeing the results quickly enough and nothing was what they wanted and all that kind of stuff.

Angela's words reminds us of the importance of the nurse or health care provider having a transparent, open, and honest conversations with family members to explain what is happening to their loved one. Evidence has suggested that understanding how to evaluate a patient's situation with expert clinical judgment can expedite holistic care, including optimal care of the body in need (Benner, 2000; Berry and Griffie, 2010; Mercadante, Villari, and Ferrera, 2003).

An Interlude Of Holding Space: Observational Stories With Nurses And Patients

The nurses' stories resonated with my own observation of an acute admission to the palliative care unit. Sitting in a quiet corner, I observed life as it is *lived* in the palliative unit. Nurses in colourful scrubs engaged in their work passed by on their way to answer various calls for assistance. It was quiet yet one could hear murmurs from nurses' conversation with their patients and family members in adjacent rooms. Laughter echoed from a room to my right, and a woman stepped out smiling. The woman, still smiling,

with tired eyes and wrinkled clothes, looked around herself and then walked to the nurses' station and asked for her brothers' nurse. She seemed content and waited for a few minutes. Then she handed the unit clerk a card [Tim Horton's] and said that this was a gift from herself and her brother to all the staff. She said that his nurse had been on her feet running all morning, and she could just see that all the nurses were in need of some refreshments.

Suddenly a scream was heard through the air, and all senses were on high alert. Paramedics rushed a young woman on a stretcher down the unit followed by a young man and an older woman. The silence was no more. The peaceful, caring space was no more; there was tension in its place. Family members and patients alike that previously lingered in hallways and common areas hurried back to their rooms; their faces grave. There was understanding in their faces. There was fear. The high-pitched scream continued. There were no words to describe it. The sound cut through the air and edges on ones' soul. Four nurses came hurrying down the hallway, and three of them entered the woman's room. The paramedics left. The fourth one, with a chart in hand, rifled through the chart and dispensed medication from many drawers. She stepped into the woman's room. Two nurses stepped out followed by the older woman and young man. They looked petrified. Tears gleamed in the eyes of the woman. One of the nurses opened a door to a designated quiet room across from the woman's room, and she stepped in along the couple. The soft voice was heard behind the door as she reassured them both.

The screams turned into sobs. The first nurse left the woman's room, leaving her colleague behind. She paged the doctor on-call, wrote down additional orders, dispensed other medication and disappeared back into the room. Quiet. At last there was silence.

The older woman and young man soon emerged from the quiet room with the nurse. The woman turned and hugged the nurse before she stepped into the young woman's room. Shortly after that, patients and their visitors started to re-appear in the hallways and kitchen. The substantial heaviness in the air had been lifted. I continued to watch the nurses as they chatted with passers-by. As I sat watching and listening, I realized how privileged I had been to be able to bear witness to the embodiment of human caring. These acute yet intimate moments were shared among four nurses; they all knew what task to perform and in what order. Primacy was not only given to the immediate urgency that was pain control for the *physical body* in order for the young woman's *body-mind* to obtain peace, but compassion which brought comfort to the distressed family members.

This observation made it undeniably real, how the unit nurses strove to assist both the patient in crisis and her distraught family at the time of admission. Striving to calm and corporeally be present and in the moment with the family at such time when nursing *tasks* take precedence in the embodied holistic and relational care of the patient and her/his family (Berry and Griffie, 2010; Larkin, 2010; Watson, 1999; 2007).

Palliative Care: Is This The Sign Of Death?

My own observations were echoed through Sarah's narrative as she described an initial encounter with a young woman being made palliative in an acute situation:

> She was made palliative and admitted urgently from another medicine floor. Her symptoms just were getting worse and worse. Her tumour had grown out of her cervix, and it smelled really badly and needed specialized dressings. She had incredible pain on urination, and she was still refusing a catheter. And because of

her ascites she had really bad nausea. I mean she could hardly sit up, and she would gag [Sarah continued] so she was rushed to the palliative care unit. But she was so afraid when they wheeled her on the stretcher, and she passed that "Palliative Care" sign, she started crying so hard. Her husband got really stressed and almost angry at both her and me. He was so stressed, telling her to stop crying while yelling at me to get her something to make her feel better.

Sarah grimaced at this memory and suggested to me that they should take the *Palliative Care* sign down. Thus she went on to say:

I mean it can be really distressing to people to see that sign, it is almost like a sign to people that this is it… that this is the end of the line for them, and they will never return. I mean if you are not emotionally ready to be palliated then seeing this sign is horrible. [Shaking her head she continued], I made sure my other peeps [patients] were covered, and then I went in the room and sat down with them and explained everything that needed to happen.

She was definitely in pain, I mean she was in total pain, you know? Well, she needed to be settled first of all, so I was able to give her something for anxiety first and then the nausea. It did not work until she had also gotten pain meds. I think the combination of all just worked. But I was also really straightforward with them like… you just needed to look like you really knew what you were doing, or they would not have trusted you to do anything right and that would have made it awful. She was exhausted after all this ordeal and after cleaning her and turning her on her side she fell right asleep…He [husband] said he hadn't seen her this peaceful in months. And she hadn't been able to lie on her side for

the longest time because of discomfort. And now she just had this look of calm on her. And she was sleeping. [Smiling].

The above encounters are eloquent examples of how nurses prioritize their care in acute situations. Such as the nurses have described, when a patient suffers delirium, restlessness or when the pain-ridden *body* is striving to breathe, nurses need to prioritize their care practices. Primacy has to be given to the vulnerable *physical body* being admitted to the palliative care space, paying noticeable attention to their bodily comfort (Hendry and Walker, 2004; Lickless, 2009).

Goldberg's study on embodied trust (2008) highlights the significance of nurses caring attitudes towards their patients. Her findings align with the storied narratives from the nurse participants in this study, emphasizing that using compassionate approaches, an open demeanour and *being there*, nurses convey a level trustworthiness resulting in a shared embodied experience with patients (Goldberg, 2008). Despite Goldberg's findings being specific to a birthing context, her work on embodied trust has applicability to other nursing environments including palliation. Trust being a fundamental component in establishing a relational, caring, nurse-patient relationship.

Sarah's narrative also illuminated how relationships between nurses, patients and families began to develop rather simply, despite the many challenging experiences that surround palliation. She stated:

After this day, we [husband and I] became very friendly. He would bring coffee and stuff for all the nurses and was always very polite. Even if I didn't have her as a patient. He would still come and ask for me, or look me up and ask me questions

or tell me that something was not right and that kind of stuff. I just connected with them from that first day, and he knew I cared.

In her article on introductory engagement, Goldberg (2005) discusses the significance of the initial encounter between a labour nurse and a birthing woman. How paramount these first interactive moments are in order to relay compassion, and build the mutual trust that ignites and sustains the embodied relationship central to the perinatal caring space (2005). Furthermore, as evident from the narratives of the participants, this also persists outside the perinatal space within other specialties of nursing. This importance is particularly apparent when working within the contextual space of palliative care with the vulnerable dying patient and her/his family.

Halldórsdóttir (2008) calls this nurse-patient connectedness the "*life-giving nurse-patient relationship.*" By meeting patients *human* to *human,* nurses are capable of empowering their patients to take charge of their illness, shift their focus from "cure" towards "optimal" health. Furthermore, this type of relationship fostered confidence in the nurses' abilities as competent and compassionate caregivers (2008). Lydia discussed a very difficult and emotional case she will always remember regarding a patient that was all alone. Not only was the patient by himself when he received the news that he was dying, but no one was with him as he was placed in the palliative care unit and placed in her care. She remarked:

> I was getting an acute admission to the palliative care unit from the Emergency department. An older European man that was just visiting Canada but was not feeling well, so he went to the Emergency department, and they discovered a stage four lung cancer with a tumor that was growing fast into the aorta. He had

just started to bleed a bit from it; nothing in gushes just trickles from his mouth. And there was nothing to be done. Poor fella, he was in such shock. And he was all alone.

Her eyes drifted towards the window as she recalled this moment. She continued:

As soon as I received the report from emerge I called a meeting at the nurses' station and told them all what was going on. And we kind of divvied up the tasks that had to be ready for when I'd bring him up to the unit. As well as they promised to look after the rest of my peeps [patients]. Angela and Aria [nurse participants] made sure his room was set up with all the tools we were going to need. I spoke with the palliative doctor and got orders for immediate sedation in case he would start to bleed out... That is how they die right…It is awful, and it is so incredibly fast. And then one of the nursing students ran to the surgery and got those blood covering towels so we could be ready for the worst.

Lydia looking rather uncomfortable shook her head as she continued:

I went to Emergency to greet him and assess him for myself. I, of course, had to make sure that he was in no pain and planned to put in a SC [subcutaneous] butterfly and start the SC infusion. It is not like the nurses in Emergency know how to act with these patients, right? But it was shocking because he was fully with it, I mean he knew exactly what was going on, he looked so vulnerable, and he was completely alone. –Lydia started crying-

Lydia's experience resonates with the eloquent words of feminist writer and poet Edna St. Vincent Millay in the sonnet *Fatal Interview* (1931).

My most distinguished guest and learnèd friend,

The pallid hare that runs before the day

Having brought your earnest counsels to an end

Now have I somewhat of my own to say:

That it is folly to be sunk in love,

And madness plain to make the matter known,

These are no mysteries you are verger of;

Everyman's wisdoms these are, and my own.

If I have flung my heart unto a hound

I have done ill, it is a certain thing;

Yet breathe I freer, walk I the more sound

On my sick bones for this brave reasoning?

Soon must I say, "'Tis prowling Death I hear!"--

Yet come no better off, for my quick ear (p.19).

Relational Space Of Care In Palliation

All the nurse participants agreed that it is the anticipation of the unknown that takes over in situations like these. Nurses are not frightened of what will happen; rather they are eager to bring the patient up to the unit quickly to be able to assess them properly. In alignment with Jean Watsons ninth Caritas process, "*assistance with gratification of human needs*" the goal for the nurses is always to get the patient's symptoms under control and make them feel safe and secure knowing the patient is now in a specialized unit where comfort, dignity, and compassion is the main focus of care (Berry and Griffie, 2010; Sitzman and Watson, 2014; Watson, 2007, p. 132).

Returning to Lydia, she stopped the interview for a moment, stepped out and returned with a cup of coffee and tissues. Smiling at me, she blew her nose and continued:

I felt so terribly bad for him being in this country away from everyone he knew and loved and then having this happen to him. It's just not fair. I called upstairs and told them I would be staying in emergency until we could bring him upstairs. And I did… We were only down there for about two hours, but I got him all settled like medically, all the right drugs and the lines and such. But then I just sat with him holding his hand, and I told him I wouldn't be leaving, that I would be bringing him upstairs to the unit. I think he just needed me to be with him, to show him empathy and compassion at this time. And just kind of, well treat him like he was still human. Right?

Lydia's story, her art, and her caring, aligns beautifully within the artistry of Jean Watson's Caring Science. Thus Watson (2012) so eloquently reminds us, "[a] truly caring nurse/artist is able to eliminate in the consciousness of the recipient the separation between him- or herself and the nurse." (p. 81).

In her story, Lydia showed the suffering body the utmost respect and dignity as she was truly in-the-moment with the patient in her care trying to alleviate his fears and anxieties about his current situation. She stated:

We talked about everything, him being from Europe, how much he loved to travel and since I'm also from another country [Australia] and have lived and traveled a lot. We had a lot in common. I think it made him feel better being able to share

with me his life, and boy he had lived. He also asked me a lot about my own life, and I told him why I had moved from my home and how I traveled Europe before meeting my husband and settling in Canada. We basically were fast friends by the time we could bring him upstairs. It was just so natural, I mean I was professional and all, but I became his friend as well. Is that weird? …I don't think so because I think that was just what he needed in that moment.

Pask (2003) maintains that the foundation on which the nursing relationship is established is the therapeutic bond that develops between the nurses giving care and the patient needing care from the nurse. This was clearly evident in all the nurse participants' stories. Pask believes that the critical element in establishing these relationships are the nurses' compassion, genuine expression of concern with the patients' display of suffering and having a desire and need to understand and relieve that suffering (2003). Wiseman (1996), however, names this concept empathy. That it is only through the power of empathy that enables nurses to enter their patients' *world* and experience it through her/his eyes. Without judgment Lydia and Sarah could understand and *feel* what their patients' *body* was experiencing and were able to articulate that understanding back to their patients. This reciprocity, [the] patients *need* to have their physical and emotional needs understood and validated, and the nurses *wish* to know their patient is what fosters the compassion in the therapeutic relationship (Pask, 2003).

Jean Watson (2012) writes in regards to transpersonal caring. "The nurse is able to form a union, a deeply human-to-human spirit-to-spirit, connection with the other person on a level that transcends the physical and that preserves the subjectivity and physicality of persons without reducing them to the moral status of objects (p. 81). It was apparent by

the narratives of all the nurse participants that they valued the healing power of the intimate, compassionate, nurse-patient, human-to-human relationship that Watson refers to. It is only in this transpersonal care that patients will thrive in the context of palliation and nursing practice.

Indifference To Care: Abandoning Moments In Time

During one of my observational shifts, I was privy to an encounter that gave me pause; I found myself questioning the nurse's decision and the ways in which she appeared to lose or misplace her ability to care. I thus began to wonder if and why she seemed indifferent to her patient and further, how this indifference influenced the care, or lack thereof, her patient (and family) received. The nurse, Barbara [pseudonym], was in the midst of transferring a patient from Cancer Care over to the Palliative Care unit. The patient was clearly very close to death, half-conscious and moaning loudly making his family very uncomfortable. Barbara sat at the nursing station and rifled through the patient's transfer papers and seemed unconcerned for the moaning patient.

The transporter asked about the room number that Barbara gave and then the patient and the family disappeared down the hallway. Shortly thereafter one of the family members rushed to the nurses' station and told Barbara that her father was clearly in pain and politely requested that she kindly give him something for pain as soon as possible. Barbara slowly looked up and said very matter-of-fact to the woman; "when I am finished here, I will be with you ." The woman apparently upset turned and hurried back down the hall. Barbara, who was not by herself at the nurses station, looked around and stated; "I mean it's not like he is going to go anywhere…Families always tend to dramatize things" and she chuckled.

From where I was sitting, I saw how Sarah [nurse participant] and her nursing student glanced quickly at each other, stood up and walked briskly down the hall. Barbara called after them that if they must go in there if they could set up a subcutaneous line for her. She received no answer, and I could see her shrug her shoulders. I followed Sarah and her student nurse down the hall and noticed that before entering the patients' room Sarah dispensed medication from the automatic dispenser and grabbed supplies. Outside the patients' room, her student waited with arms full of fresh linen, washbasin and hospital gown. With those in hand they entered. I did not see them again for a while. However, I could hear low conversations going on in the patients' room. Barbara, still sitting at the nursing station, chatted away with the other nurses. I watched the other nurses' faces. They all witnessed what had just happened. I felt I could read indifference in some of them and distaste in one very young nurse.

What I observed, was not the beginning of an engaging nurse-patient relationship (Goldberg, 2005; Larkin, 2009). Moreover, this continued when Sarah and her student returned to the nurses' station to inform Barbara that her patient was clearly in the last stages of dying. Barbara got to her feet and walked down the hall. "Do you want to see"? She called to Sarah's student, who then followed her down the hall to the patients' room. Half an hour later, as I was talking with Sarah, Barbara reappeared at the nurses' station with Sarah's nursing student. She phoned the physician on call to inform him of the death and prepared needed paperwork. The student was visually upset, and it was obvious she had been crying. Sarah comforted her and asked if she would like to talk in private. Barbara turned towards them and commented that she [the student nurse] shouldn't take

this so personally. "I've worked here for decades and death does not affect me at all. I have learned to not take the job home with me, and one day you will learn too."

After reflection, I did not believe Barbara's words and behaviour were in any way meant in malice, although not reflective of current professional practice. Rather, as a nurse educator, I felt her abrasiveness exemplified what not to do in clinical practice. In their article, Piscotty and Kalisch (2014) discuss the implications for health care providers when they miss opportunities to care and the implications for the nurse-patient relationship. Watson (2012) calls this the *uncaring* moment that happens when a nurse fails to see the nursing act as unique and is blatantly un-sensitive to another's needs or feelings (pp. 44-47).

Unlike the nurses in this study, Barbara appeared not to view the death of her patient as an intimate moment in care. Moreover, as evident by how visibly upset the student nurse felt and Barbara's dismissiveness, she failed the student nurse in her role as a mentor in caring for a dying patient. Insofar as expert nursing knowledge develops through the attentive guidance from the more experienced nurse to the novice nurse (Ryan et al., 2010).

While Barbara's language and behavior lacked professionalism and negatively influenced the patient, it must also be understood against the institutional landscape of health care. One in which gender, power, and hierarchies have historically challenged nurses in pervasive and systematic ways. Because the majority of nurses are women, it is not surprising that many suffer with significant degrees of moral distress, chronic fatigue, and burnout (Austin, Bergum and Goldberg, 2003; Green, 2012). Thus, one might ask if

Barbara's outwards indifference to care, not only with her patient but also with colleagues and the student nurse, are partly explained by the aforementioned.

Moreover, as Goldberg (2005) reminds us, based on findings from a feminist phenomenological study with nurses and women in the context of hospitalized care:

> …some of the nurses also discussed situations that occasionally positioned them in ways that resulted in treating women as disengaged others, diminishing their relationships with the women in their care, although they desired to do otherwise. Language, circumstances, and barriers to practice have all interfered with introductory moments of an engagement, positioning both nurses and women in situations that prevented them from appreciating women within the particulars and context of their lives (p. 406).

In returning to Barbara, her lack of professionalism, independent of the reason is nevertheless challenging to reconcile in light of a dying patient in profound pain. Yet, many scholars argue that professionalism entails a distancing from the patient. Hanna and Suplee (2012) suggest that nurses should be discouraged from becoming involved on a personal level with their patients and families. Their stand echo's Armstrong (1996) that nurses often don't know when the boundary has been crossed in the nurse-patient therapeutic relationship or grossly violated. In their paper, they discourage nurses to become involved emotionally with their patients; this includes doing favours for them or divulging any personal information (Hanna and Suplee, 2012). This direction is in stark conflict with the practice the nurse participants were performing for their palliative patients and their families.

Re-Claiming Moments In Care: Professionalism Beyond The Boundaries

Chiara recalled: "I remember this one patient who loved a certain drink, so I would go down and get them that drink every day because there wouldn't be family coming in. I'm not sure we are allowed to, but that kind of built up a rapport. Right?"

Chiara clearly felt she was overstepping her professional boundaries by getting her patient coffee. She continued as she described how she spent frequent moments trying to build a rapport with a patient that was quite depressed and didn't want to talk with anyone. With gleaming eyes and obvious pride, she smiled as she stated:

I found out from his family, as he would not say it himself, that he was a huge golfer, like a massive golfer. So while I was in his room, I would start talking about golf, and then I started talking to him about how my husband used to be a professional golfer. And even though he still didn't quite talk with me rather just snorted- but guess what the next day, don't I get a pack of golf balls from him. She laughs as she remembers. Then he finally started opening up to me, like through my husband... and where they had played golf and if they were any good and such. [Smiling] It did break the ice for us. It really did.

Gadow (1980) wanted to blur these rigid lines between a patient [*sick body*] and the *professional* nurse and the practice boundaries commonly favoured by governing nursing bodies (National Council of State Boards of Nursing [NCSBN], 2011). Gadow encouraged nurses to reveal parts of themselves to their patients, give a glimpse of the person who was hidden underneath the starched uniform. Furthermore, she believed that

a personal involvement, in the context of care, between patient and nurse, allowed for a much greater and more intimate relationship to form (Gadow, 1980).

Todays' leading nurse scholars have a more favorable view of the nurses' capability to act in a professional manner, that still enables them to meet the patient and their family at a more intimate humanistic and holistic level, and within a caring space with mutual understanding of unspoken boundaries and trust (Benner, 1984, 2000; Bergum, 2003; Bergum and Dossetor, 2003; Berry and Griffie, 2010; Gadow, 1980, 1999; Goldberg, 2005, 2008; Larkin, 2009; Ryan et al., 2010; Watson, 1999, 2006, 2012).It is well established that patients and family members need to have a certain level of confidence in the nurses' practical knowledge and skills before a trusting relationship can be developed. Furthermore once competency has been established; trust is a natural consequence (Raeve, 2002; Belcher and Jones, 2009).

As is evident from the stories from the nurse participants, nurses have to meet patients on a human-to-human level and be willing to share honestly of themselves with patients. Only then does the nurse have the ability to cultivate an engagement that is relational in nature and has the potential to grow and flourish, for the nurse, patient, and family (Pask, 2003). However, this openness and sharing can be problematic for nurses that lack self-confidence or have less than optimal communication or relational practice skills. Specifically as nurse-patient relational engagement requires inquiry that is guided by conscious interaction including therapeutic listening, questioning, empathy, mutuality, reflection, reciprocity and sensitivity (Doane and Varcoe, 2007; Larkin, 2009). As a mutual bond with the patient or her/his family is crucial in the development of a trusting and caring relationship (Thorne and Robinson, 1988).

Historically women have been referred to as lesser, the weaker and the submissive (De Beauvoir, 1949). Young and Allen (2011) suggested that "all oppressed people suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts, and feelings" (p. 40). Only by reclaiming the power and give it voice within the practice environment, can nurses and patients have a true human-to-human relationship built on equality and respect (Butler, 1997).

This resonates firmly within Watson's (1999; 2012) theory of human caring. She reminds us that a true caring moment cannot occur unless both the nurse and the patient are mutually invested and *present* in the relationship. For Watson, the driving force behind the developing relationship stems from a genuine desire to be compassionate, authentic and selfless in the act of caring (1999, 2012). Therefore, as the foundation of the caring relationship is established through these initial moments, the importance of the initial interaction between nurse and patient or nurse and family member cannot be enough emphasized (Goldberg, 2003, 2005, 2008).

Whether the nurse is engaging with the partner of a labouring woman as in Goldberg's (2005) study or comforting a distraught husband of a palliative patient, the mutual creation of a caring space, and the ability to hold the space, is essential to connect on a much more emotional and personal level with patients and their family members (Hearth and Cutcliffe, 2002; Sheldon, Barret and Ellington, 2006). As Chrystal stated in the context of the study: "I became very close to them [family] because I tended to their needs, and I made them a priority. I was knowledgeable about the drugs the patient needed, what was going on and such." Including the family in the caring space and engaging with them in a relational manner conveys the message that the *family* is truly

significant and that the nurse *cares* about them (Barry and Griffie, 2010; Halldorsdottir and Hamrin, 1997). Thus Chrystal continued:

> It was a very sad admission. I mean the patient had just been on surgery, and they were all so hopeful.But then they opened him up and just closed him up again and made him palliative. So all of a sudden the family was bringing him to palliative care to die. I mean they knew he was going to die like within days. I had read his file ahead of time, so I sort of knew what was going on before they came and was able to make the family feel I knew what was going on right from the start. That really builds trust. They feel like they matter when you take time to investigate yourself instead of asking them all the questions.

Angela had similar reasons for why she tried to connect with the families of her patients. She commented on the following:

> All you want to do is help them relax a little bit. You almost take on the family's fears and all that kind of stuff as your own. You only know them for a couple of days—she was only there for a few days—but just the thanks, they look at you differently, and you are almost like a little guardian angel to them because you finally got them to where they are comfortable with what we do. It is hard to put someone into a palliative unit, it is hard to know that they are dying, but to make the family comfortable with what's going on, it is a nice feeling. And likeI said to the family, I said: You know what? It is what I do. I said nobody wants to see what we've seen in the past couple of days, but as long as they're happy and they're content, the patient is sleeping, the patient is calm, the patient is comfortable.

Chrystal attempted to understand the complex relationship she had built with a dying patient in her care. She continued:

They had a sense of trust in me because I had knowledge, I was confident, I was mature, and I was experienced. And I made sure that I tended to the needs of the patient. Was respectful you know. She [wife] stayed overnight, but the children went home. Then as the patient condition deteriorated she became frightened that he would suffocate and die in pain. The only thing I could do was to sit with her and reassure her that he wasn't in any pain, and he was not struggling to breathe. She needed me to tell her over and over again that he [husband] was going to have a peaceful death, and I just sat there with her. Until it was over.

Sometimes the potential relationship between nurse and patient or nurse and family struggles to blossom into the trusting relationship ones strives for (Askinazi, 2004).With no one person to blame, it is simply the inability to connect with another person. To meet on that profound plane of humanity that allows for the creation of the trusting relational interaction to take place (2004). Chiara commented:

Sometimes you've exhausted every possibility and every avenue to show them that you care, you either empathize or try to get them to understand or that you really care about them. But they are just not open to listening to you. And you know in your heart that there's nothing else you can do in that regard. You have even talked to the physician and gotten every order changed. Tried everything and it is still not enough for them…it is difficult dealing with very, very difficult people. And they are just angry, right? And it is just easier to blame us for being

incompetent than blaming their loved one for getting so sick. We have just to

account for those emotions and not allow it to fester.

Unfortunately, conversely, the interpersonal characteristics of relational nursing

are often reduced to set of behavioral skills (Doane, 2002). Chiara continued:

It is interesting I usually have such wonderful experiences with both patients and

families, but it is the ones' that question your integrity and abilities as a caring

nurse that you… well… Remember so clearly.

Sarah discussed how at times she has difficulties establishing a rapport with

patients and their family members. She stated:

For some reason, even if they have been there for a while, they [patients and

family] just don't have this trust with you and see you just as a nurse… You

know, as an object. Like it is just a 9-5 job for us and that we do not really care.

Discussing this topic became quite upsetting to Sarah who waved her hands as she

continued:

You know it is really hard when you feel that they only see you in this light. The

one that only does what the doctor told us to and bathe's, gives meds and such.

Not a real person to connect with on a more personal level. They just are unable

to relate to you in that way. You just have to know you're doing the best you can

for them and the patient regardless.

As Sarah's words illuminate. Nursing as a scientific caring profession where the

majority of practitioners are women continues its struggle to break the constraints of

institutional hegemony, inequality and gender stereotypes (Summers and Summers, 2009). Sarah felt as this person was unable to acknowledge her as a learned professional that encompassed skills and abilities. She felt objectified as *only* a nurse, *only* a woman. Today, practicing nurses suffer duress when projected as such as opposed to the powerful, resourceful and intelligent women scientist they are (pp. 118-145).

According to Brennan (2005) nursing was developed within an altruistic domain. As Young (1990) described; a female nurse according to the institutional hierarchy was only capable to attend to the simplest tasks delegated to her by the patriarchal male doctor. Cultural fiction and media still depict nurses in such light that it makes it challenging to demolish the obscured image of nurses' obedience and servitude (Summers and Summers, 2009). To emancipate the nursing profession from the outdated norm of the past, nurses have to find their voice and grab the power themselves to have a say in projecting a true reflection of the modern professional nurse. Rousseau (2004) asserts that the display of power that occurs when bedside nurses are dismissed and excluded from participating in discourse concerning their patient is deplorable and blatant professional disrespect.

To be seen as a whole person beyond the boundaries of your practice, title and the scrubs you wear is something that Chiara has aimed for in her practice. Finding that common ground, a mutual interest, as in the shared love for the game of golf. She continued:

> There are these identifiers [love of golf] that help you relate to each other on a
> personal level, and I think that helps. Right? They do not just see this nurse in the
> white kind of scrubs sort of thing. Right? They start seeing you as a person that

really cares about them and what happens to them. Like they matter to you and that you are interested in them. So if you kind of personalize yourself and that kind of helps them open up and probably be a little bit more trusting of you and in your abilities.

Conclusion

Throughout this chapter, I addressed the theme, *the embodiment of human caring: attending the physical body during palliative admission*. By way of analyzing the participant narratives and own observational data, I emphasized the significance of those initial encounters that occurred during the acute admission to palliative care. How the foundation for a trusting relationship between the nurse and patient and his or her family is firmly established during these initial moments. I discuss how nurses expertly shift their focus from the task oriented caring space where acuity centers on the suffering body, towards the creation of a more transpersonal intimate relationship. In that, once the physical body has been relieved of the acute symptom, the nurse/patient and nurse/family relationship transitions towards the building of a caring and mutually trusting relationship.

Engagement that is relational is a way of knowing that emerges when a nurse and patient/family create a caring relationship through mutual bodily sentient. I illuminate through the participants' stories, how through relational engagement and dialogue, all parts that make up the body are cared for in such way it fosters the trusting connection that allows nurses to attend to the physical, mental, emotional, and spiritual body where primacy is given to the whole body allowing nurses and patient to foster and attend to their relationship and become mutually engaged partners in care.

Chapter IV

Coming To Know In The Nurse's Engagement Of Hope In Palliation

"The very least you can do in your life is figure out what you hope for. And the most you can do is live inside that hope. Not admire it from a distance but live right in it, under its roof." (Barbara Kingsolver, 1990, p. 328).

The *coming to know* as it relates to the care of the patient being palliated has been identified as "the essential antecedent for the provision of good quality care" (Luker, Austin, Caress, and Hallett, 2000, p. 777). In the following chapter, I illuminate the storied narratives of the nurse participants as they relate to the theme: "*Coming to Know in the Nurse's Engagement of Hope in Palliation."* Carman and colleagues (2013) suggest that to be sincere in the quest of *coming to know* takes a genuine interest and willingness to be invited to share in the lived world of another. This chapter highlights how nurse participants embody the nurse-patient relationship by way of mutual engagement, trust, respect, and relationally (Carman et al., 2013; Goldberg, 2005, 2008; Watson 2007, 2012). The relational caring environment creates a safe space for patients and their families to mutually share with the nurse, their innermost feelings, fears and hopes regarding their illness and impending death without judgement or false reassurances (Dunne, 2005; Olsman and colleagues, 2014). The sanctity of the caring space enables nurses and patients to *come to know*. And as partners in care, explore the physical, psychosocial, and existential needs of patients through self-reflection in search of meaning and hope in everyday existence, beyond suffering (Kylmä, Duggleby, Cooper and Molander, 2009).

Coming To Know - Perceptions Of Hope

Patients and their family members frequently find comfort in discussing their hopes, fears, and anxieties with a trusted nurse (Sullivan, 2003). As Sarah, one of the nurse participants stated:

Hope is everything. To have hope is to have a reason to wake up the next morning. Maybe they wake up hoping they will be able to have a regular solid breakfast, or they might hope to be able to sit upright in a chair for their breakfast. I know some of my patients hope that I will be their nurse for that day [laughter] it's because they know me and my story. But I try so hard not to show them my sadness for them, so I talk and talk, and then I talk some more and they listen, and gradually they start to talk back and *voila* we are friends. And that's when I probe and prod them for their hopes, needs, likes, and dislikes.

Sarah paused for a while deep in thought before she commented: "I mean if people don't have anything to hope for… what is there to live for?"

As Sarah's narrative highlighted, everyone has a story to tell. Bisognano and Goodman (2013) proposed that human beings are innately storytellers and become connected emotionally by way of relating to the *others* story. To discover the world lived by another allows for reflection on one's own life, which has the effect of getting people to hope, and maybe to experience new things themselves. The conversation that people need to have is personal, not medical, and the best way to draw people into the conversation is through storytelling (2013). Chrystal believes that no hope takes

precedence over another. That it is what the patient hopes for in the moment that matters. She stated:

> Hope can be anything. So I guess sitting down and talking to them and asking them is there anything that's on their mind…. To find out if there is anything that they are wishing for or hoping to see or do before they pass away. Maybe there is a family member that they would like to be at peace with, you wouldn't believe how often that is the case. Or, [Chrystal laughs]… It can be as simple as me sneaking in their cat or a dog for an hour or two. Sometimes it can be as simple as that. Right... Hope can be as simple as hoping for a private room in palliative care.

Creating a safe and welcoming caring space for patients and family allows for an authentic forum to occur permitting both the family and the patient to voice their fears regarding the impending death, reframe their hope and set new obtainable goals (Barry and Griffie, 2010; Sullivan, 2003). Chrystal continued:

> You actually have to talk to them and understand where they are on their journey. Because you know what... everyone is at a different place. Some people are grateful that they had six good years before needing this level of care. They were told they only had three, so their family has been given three extra years. They had time to come to terms with death and prepare themselves and their family for the inevitable. While others are angry and feel ripped off because they only just got the diagnosis, and the disease is too advanced so now they are being given palliative care. You look for signs that maybe they're willing to talk now. Right? Or if they are ignoring you completely, you just assume they're listening so I just keep talking and hopefully they're listening. ….Patients that are dealing with

anger, at the world, their disease or even themselves, are the most challenging. It's really difficult to connect to someone that is angry. They are not ready to talk about hope or daily goals because they are just stuck in this feeling of anger. We have to respect it and give them time. It just takes time. Sometimes a lot of time.

Angela agreed with Chrystal as she reflected on hope in relation to the patients in her care. She commented:

Sometimes you need to investigate what exactly the patient is hoping for… I mean sometimes you have to interpret what their hope is, right? And then act accordingly. It's like reading between the lines to figure out what they actually are hoping for. Sometimes it's not at all that obvious, or they might not be able to tell you because it's just too painful for them.

My hope is that they're comfortable, that they're not in pain, that it's a smooth transition. [From active treatment to accepting palliation]. You hope that you have done all you can to make the transition as smooth as possible. My hope is that it's painless, that the family is okay with it, they're coping well…. to calm the family's anxiety to make the process a lot easier for the patient. And giving them the support that they may need.

Angela paused before she continued:

I always think that being at home is better for your psychological well-being. Nobody wants to focus on the same four walls all the time. You get a hospital bed in the living room; they're still at home …still surrounded by their family.

Only by *knowing* do we as nurses stand side-by-side with our patients, cognitively grasping their emotional and situational reality.

Duggleby, Bally, Cooper, Doell and Thomas (2012) recommend that nurses and other healthcare professionals invest time to get to know their patients in order to discover their wishes and desires for the few precious moments that remain. The *how are you* question in palliative care cannot be asked without substance. It should relate a genuine and authentic desire to discover how another person is feeling physically, emotionally, and spiritually, as well as support and acceptance of their choices (Cameron, 2004). Cameron, (2004) also indicated that asking this question, gives way for a relational space where patients and nurses can engage by sharing their stories and express their feelings.

Thus, the act of coming to know empowers patients to enjoy these precious moments to the fullest as well as enables the acceptance of impending death (Duggleby et al., 2012). Coming to know another person to the degree of intimacy suggested above requires both attentiveness and saliency on the part of the nurse (Cameron, 2004; Goldberg, 2005). Reflecting a caring presence by attending *to* and spending valuable time *with* patients and their family members, can inspire and actualize hope by keeping the notion of achieving goals, desires and wishes alive (Richardson, MacLeod, and Kent, 2012). All the nurse participants agreed that being physically and emotionally available for patients and their families provided support during times when patients' or families' own hopes wavered. Aria stated:

When a patient feels overwhelmed with whatever they have just been told or been thinking of, you cannot downplay that feeling of hopelessness…It's something

they have to go through and work out themselves. I try to be there for them, get them to talk and I listen, and then hopefully you can eventually assist them in building up hope again.

Nevertheless, this can only be achieved with assistance from within the institution where nurses work. This entails that time must be available within institutionalized care to support the nurse-patient relationship, despite the modern day realities of high patient acuity and decreased staffing ratios (Austin et al., 2003; Santos Salas and Cameron, 2010). Austin, Lemermeyer, Goldberg, Bergum and Johnson (2005) argued; "We frequently find ourselves in the middle of a tug-of-war, residing in the tension between the powerful institutions and administrators that employ us and the patients with whom we engage" (p. 45). Brianna's words reflected this frustration as she stated the following:

We just have to make time! If things aren't stocked before shift change or some other task is left unfinished… well so be it. These patients don't have much time left, and I think we just have to appreciate that maybe the best way for us to show that we care is the gift of uninterrupted time…In today's fast-paced biomedical paradigm, most nurses don't have enough time to give patients adequate care.

The aforementioned narrative by Brianna echoed in the comments by Austin and colleagues (2003), as they remind us that "the resources necessary for attentive, competent, ethical practice have to be available if nurses and others are to fulfill their commitments" (p. 182).

Hope As Engaged Care

Evident through the nurse participants' stories is that one cannot foster patients hope without taking the time to discover what the patient desires in the context of her/his illness. Chiara discovered this after coming in for an overtime shift after vacation, and her assignment included five patients that she didn't know. I come across Chiara during one of my observational shifts as she wheeled a patient towards me, returning from the neighboring unit. The patient, sitting hunched in his wheelchair was middle age, freshly shaven, with wet hair and wearing clean checker-patterned pajamas. As I greeted them, the patient looked up and grinned at me from ear to ear. I realized he was shockingly emaciated. Only then did I notice the woman standing beside Chiara holding a urine bag and a Hydromorphone CADD pump (Ambulatory infusion pump). She was also smiling widely. "You look like a cat that just found cream," the woman said half laughingly and poked the patient. He laughed; his thin shoulders trembled as he looked back at Chiara and stated: "Well I ought to be… right, it's been six months since I've had a soak; And this little angel… [he nodded towards Chiara], well this was as close to heaven I will get… without actually being dead" [he laughs]. The woman [his wife] nodded her head in agreement. Yes, she said… it's true, he's waited six months for this.

Later Chiara discussed how this man had been wheelchair-bound for six months since his prostate cancer metastasized to his spine had left him paralyzed below the waist. And it had taken weeks just to get his pain under control. She continued:

This morning when I met him and introduced myself I asked him [like I ask all my patients] what he wished to do today. And he at first just kind of shrugged his shoulders. It took a bit of prodding before he told me that what he wanted was

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impossible. I, of course, assumed he was talking about his disease or dying, but then he told me it was to take a proper bath. A bath… Chiara exclaimed... who knew. He said that he was a bathing man [laughter], and in his bedroom at home he has this great big tub that he use to soak in every night before bed. He said that the nurses had told him that the unit didn't have a tub room and offered him a shower instead… but it's not the same. I [Chiara] thought about it for a while, and then I remembered that the general medicine unit on the west side has a tub room. So I told him it would be my mission for the day, to get him dunked [laughter]. I explained that it might take a while though and even though he kind of looked excited he still had that look… you know like he knew it wouldn't happen like he didn't believe me. You should have seen his face when I told him we were going for that bath! Now that was priceless. –that's why I can do this job you know, the gratitude I receive… for the tiniest things.

Chiara [smiling], further stated:

He really is such a wonderful man, very quiet and aloof. He's been through hell; chemo didn't work at all, then surgery, and after he became paralyzed they tried radiation. Nothing so far has worked. He's been back and forth from neurology, complex care, and ICU these past six months until becoming palliative a few days ago. Chiara sadness on her face continued: They [doctors] say he only has a few days left. I just had to get him into that tub no matter what [smiles].

Two weeks later Chiara came to find me and tell me that he [patient] had passed away. She told of the close relationship that was built because of what she called *only a*

bath. "We spoke and laughed every time I saw him until he slipped into unconsciousness on his very last day and died peacefully."

Coming To Know Through Journey Of Hope

In what follows, Brianna recalls a caring relationship with a patient that touched her soul. Still to this day, she carries her memory in her heart. She remarked:

> You know…you meet these patients, and golly I've met many. But you never quite expect, and you're never really ready when you are faced with a patient that will touch you, or move you in such a way it will impact your whole outlook on life. I have been a nurse for more years than I can recall [laughs], and I love it, from the bottom of my heart and the deepest corners of my soul… I truly love it. What privilege. Brianna stopped abruptly, then looked up at me and with a look of awe she repeated… what privilege. To me caring for people at the end of their marvelous journey that is their life, is such a privilege. I believe we all have a purpose in life, a destiny of sorts, and I know it in my core that I've found mine. I'm a fellow traveler, granted the gift to bear witness to these peoples' journey towards the hereafter.

> I bonded with her; I felt connected to her on a high spiritual level. I know this is not something that as a nurse we are supposed to do… but she was so much like me and my sisters, maybe it was the fact she was Scottish [chuckles], and we are all a superstitious bunch, seeing things that no one else sees and such.

> Brianna smiled as she continued:

She was so beautiful [patient] her green eyes always seemed to be looking far away, deep into the sky as if seeing something beyond this world. A tiny woman stuck in that big hospital bed, she asked no questions, made no demands of anyone, had no complaints. Brianna frowns as she continues: I knew she was suffering; I've been a palliative nurse for so long that I can read the non-verbal signs of pain and that *wee lass* was in pain. But she never complained. She was at peace; she was content.

Her husband, on the other hand, was angry. Angry at the world, angry at us the nurses that took care of her, and most of all he was angry at her [patient]. I, of course, knew from experience he was just experiencing anticipatory grief. All he needed from me was compassion and time to forgive her for leaving him. He stayed by her side, continuously holding her hand, smiling, telling her God would cure her, that she needed to get stronger that she needed to want to beat this. It broke my heart listening to him go on and on about these unrealistic things. I understand he just needed to put these hopes into the universe, but he knew there was no hope for a cure.

One night as I am rounding on my patients, the husband signals me to join them. He tells me they had been discussing ways for her [patient] to get her final wish fulfilled. She wanted to die in a hospice in Edinburgh and be laid to rest next to her parents. AND they wanted me to accompany them on their trip, as her nurse/companion. That they had a very tiny window of opportunity, do go forth with this so it would have to be right away.

I was absolutely flabbergasted. The thoughts that ran through my head were incoherent. Me… go with them to Scotland, for how long? Would I be able to get time off work? Can I afford it? Was it even legal? [She laughed]…

It took me all of the five minutes to say *YES*, of course, I'll escort you home. Anyhow to make a long story short, after that decision had been made everything moved fairly quickly. There were fundraisers held; all the paperwork got signed; ambulances were booked at both ends. I had a bag full of her medications and supplies and voila off we went. I will not say it was a smooth flight… although we were treated well by the airline staff and the other passengers. But there were occasions where I thought she wouldn't make it across the Atlantic, this took a lot out of her. I recall thinking how poetic it would be, dying in the clouds.

Brianna [smiled]. I did Reiki on her (the laying of hands, allowing the unseen life energy flow through them) for the most part of the trip, willing my own energy to flow towards her, to energize her a little. I don't know if it helped, but we made it to Scotland.

Upon arriving in Edinburgh, we were met by an ambulance and a taxi to take us straight to the hospice. I can never forget our arrival. As I step out of the car and face the old Victorian house, double doors open and a woman clad in a long flowing dress greets us. With arms, outstretched she proclaims *welcome* be *welcome*. I felt like I had arrived home. The love illuminated not only from this woman, this nurse, but the whole house was somehow saturated with love and peacefulness. Nothing was sad or gloomy only light airy and well… happy.

Soon after, I made my last farewell to my patient as she lay semi-conscious in her new room. I could only watch her in wonder, in awe. This unique person, this woman. Many times in our role as healers, we strive to give hope when there is none to be had. We often feel sorrow for the soul that is about to journey beyond the boundaries of this world. But at this moment, as I watched this beautiful woman I saw not sorrow or regret. I saw someone so strong, so courageous, so brave and so incredibly at peace with her mortality.

Brianna was obviously shaken by the recollection of this patient and what she discovered about herself during this journey. A selfless act of caring directed at *another* had ended up being an epiphany of self-enlightenment for her. Her narrative left me breathless and moved in deeply profound ways. I have frequently reflected back on Brianna's experience and why it stayed with me for many weeks following the interview: I realized perhaps it was her innate goodness, her ability to reflect love and positive energy back into the world without expecting anything in return. The exuberance of Brianna's wisdom, her agency and confidence humbled me. This strong personality occupies a relatively tiny *body*.

Young (1980) stated, "the space, that is, that is *physically* available to the feminine body is frequently of greater radius than the space that she uses and inhabits." (p.40). However, Brianna's presence in our shared space was so powerful it was almost tangible. She didn't situate her body in such way she would occupy the least amount of space. She spoke *through* her body, *with* her whole body, hands animated as she used her body to relay her story. A self-assured woman that is one with the world and confident in how she fits within it.

Listening to Brianna's story, I am reminded of a poem by Emily Dickinson (1922), named *Time and Eternity* that captures poetically what Brianna's story *feels* to me.

THE LAST night that she lived,

It was a common night,

Except the dying; this to us

Made nature different.

We noticed smallest things,—

Things overlooked before,

By this great light upon our minds

Italicized, as 't were.

That others could exist

While she must finish quite,

A jealousy for her arose

So nearly infinite.

We waited while she passed;

It was a narrow time,

Too jostled were our souls to speak,

At length the notice came.

She mentioned, and forgot;

Then lightly as a reed

Bent to the water, shivered scarce,

Consented, and was dead.

And we, we placed the hair,

And drew the head erect;

And then an awful leisure was,

Our faith to regulate (Emily Dickinson, 1922, pp.130-132).

Hope In Kindness And Comfort: The Act Of Tea And Conversation

"While there's tea, there's is hope" (Pinero, 1988)

As I got ready to leave one of my observational shifts, I saw a few people gathering at nurses' station. They looked like they were waiting for something. However, they just stood around patiently. I walked towards them and as I overhear them talking it dawned on me that they were discussing the quality of the cookies. Will it be lemon curd like last week? Or maybe oatmeal? I bet it will be chocolate chip and oatmeal said one of the women to the man standing next to her. She turned to the nurse sitting closest to her and exclaimed: He [patient] has been waiting for a whole week for her [volunteer] to bring him his tea and cookies. She laughed as she continued: It's about the only thing he'll eat now, and he so looks forward to Thursdays. I don't know how she does it, he [patient] doesn't want the cookies I bring him. But she [volunteer] shows up, and he eats everything she hands him. That woman just has this aura about her; she is truly an angel.

As she spoke this, a beautiful elderly woman walked briskly towards the nurses' station pushing a large two tier serving cart. On the bottom shelf were three *steaming hot*

gorgeous antique teapots and stacked teacups. They were all shapes and sizes, none like the other, every single one unique. They were pink and blue, yellow and purple, green and orange. Some were covered in flowers and others with butterflies. One cup even had kittens on it. The only thing they have in common is that they were all old, beautiful, delicate and unique. The top of the cart was laden with various home-baked cookies and to the obvious joy of nurses and visitors alike: The carrot cake. The woman gracefully served those waiting patiently for her at the desk, before she headed towards the patients' rooms.

Moving from one room to another, she poured her hot brewed tea and handed out cake and cookies, pausing at every bedside, stopping to chat and laugh with patients and family. She lingered a bit longer in those rooms where patients were nearing their moment of death. I saw her give a family member a big hug. I followed her quietly in awe. She was reminiscent of a ray of sunshine. Her demeanour and stance radiated authentic kindness and caring. It was obvious to all that were present that this was a unique woman, who with her tea and homemade cookies sprinkled a bit of hope and happiness wherever she went.

As I sat and partook in the delights of the tea, cookies, and cake, I was reminded of our historical legacy as nurses: one where nurses have battled a gendered past to move beyond a feminized interpretation of caring, and yet, has lost the art of this crucial foundation of our practice. I became acutely aware of the simile the image of this remarkable volunteer calls forth in my mind. As she walked room to room with her assortment of tea and cookies, I imagined that this was how Nightingale must have appeared to onlookers as she rounded on her patients in Turkey. Walking room to room,

moving from one patient to another, with common sense and critical mind, like a concerned mother, pausing to assess each and every one of her patients using her own hierarchy of needs. She wrote: "It [nursing] ought to signify the proper use of fresh air, light, warmth, cleanliness, quiet, and the proper choosing and giving of diet –all at the least expense of vital power to the patient" (Nightingale, 1861, p. 5).

According to de Beauvoir (1953) home-making is a non-paying domestic servitude to men and children assigned to women after they have been *given* in marriage to men by other men [fathers] (pp. 417-419). Young (2005) argues that de Beauvoir oversimplifies this situation as there is much history embodied in homemaking and keeping the meaningful artifacts of one's home (p. 141). Traditionally women are not only the keepers of their own history embedded in these objects, but preservers and storytellers of the embodied history of those who came before. Living in the world, within ones' home, surrounded by objects and keepsakes from ones' life as it has been lived and experienced, confirms who we are in this world and how we belong within it (Young, 2005, pp. 141-143).

How Do You Take Your Tea? –Coming To Know Through Serving Tea

In her *Notes on Nursing for the laboring classes*, Nightingale (1861), commented on the usefulness of tea, "the only English patients I have ever known refuse tea, have been typhus cases, and the first sign of their getting better was their craving again for tea" (p. 53).

The origins of tea dates back to 2737 BC and Chinese Emperor Shen Nung (Pettigrew, 2004; Ruben and Gold, 2002). The Emperor, who only drank boiled water

was resting under some trees when a few leaves drift into his cup and his entourage, were boiling water under open skies, when leaves from a nearby tea tree end up in the pot, resulting in the miraculous but accidental discovery of the worlds most celebrated brew. In the 7th century AD, tea found its way to Japan were the making of tea, and serving of tea, developed into highly ritualistic ceremonies still considered to be an important part of Japanese culture (Ruben and Gold, 2002). Trade routes from Chine paved way for tea to enter Europe in the early 17th century. Although introduced first in Portugal, Holland, and Germany and fairly popular among all social classes, tea became an instant sought after commodity in Great Britain were in 1658, the "China Drink" was advertised to be an excellent cure for all that ails the human body and *physician* approved (Pettigrew, 2004).

What has come to be known as *afternoon tea* was introduced to British society by Anna, the Duchess of Bedford, who is credited with the invention of afternoon tea in 1840. She is said to have experienced great hunger in the afternoon due to the long gap between lunch and dinner. To combat the hunger she started to invite her friends over for afternoon refreshments that constituted of serving of tea and small cakes or cookies. This ritual took a firm hold in Britain and today *afternoon tea* has become a classic British institution (Pettigrew, 2004).

Trollope (1862) asserts that the rituals of the tea table suggest that by consuming tea, men participate in the production of domesticity. The mutually beneficial moral influence of the home is rendered meaningless if the man of the family fails to return to his wife to accept the nourishment she offers. The author warns that without the social lubrication of tea drinking, the English nation would lose their sense of self and their proper role within their family and their society (p. 181).

As stated by Barbery (2008):

"When tea becomes ritual, it takes its place at the heart of our ability to see greatness in small things. Where is beauty to be found? In great things that, like everything else, are doomed to die, or in small things that aspire to nothing, yet know how to set a jewel of infinity in a single moment?" (p. 85).

The ritual of serving tea has always been a gendered custom as is evident in Beauchamp's (1999) narrative: "As a ritual engaged in primarily by women, the serving of tea is a dominant symbolic act, expressing the asymmetry between the sexes. Through pouring tea for men, women express their deference for them and their inferiority to them. At the same time, serving tea is a symbolic act linked to women's role as nurturer, a function assigned to women on the basis of sex in most of their social roles. In this sense, the tea-serving ritual accentuates the differences in behavioural expectations for the two sexes while ceremonially acknowledging and approving the traditional functional justification for them (p. 223).

The simple ritual of serving tea is eloquently revealed in the poem *Afternoon Tea*.

My copper kettle
whistles merrily
and signals that
it is time for tea.

The fine china cups
are filled with the brew.
There's lemon and sugar
and sweet cream, too.

But, best of all

there's friendship, between you and me.

As we lovingly share

our afternoon tea (Arolin, 2008, p. 78).

The art of serving tea, in all its simplicity can be viewed as a mundane womanly task that one performs without much thought or effort. "I'll be mother" [I will serve] is a statement laden with historical traditions and underlying implications. However, in context of nursing, serving tea [I'll be mother, I will take care of you] and engaging patients in conversation can be viewed as fundamental in the *coming to know*, as one asks *how do you take it?*

Creating Caring Space For Hope Within Institutionalized Health Care

The caring relationship can quickly be damaged by negative comments and false reassurances, as well as avoidance of sensitive topics altogether (Sullivan, 2003). By circumventing challenging questions, avoiding participating in meaningful discussions on sensitive subjects or even blatantly disregarding signs of psychosocial distress. Nurses that indicate with their demeanour or behaviour that they are reluctant to invest in building a caring relationship further contribute to hopelessness and even distrust of the entire care team (Sitzman and Watson, 2014; Sullivan, 2003). While nurses may regrettably engage these unintended behaviours on occasion, the biomedical model of healthcare may further isolate, objectify or alienate patients based on the institutional landscape grounded in gendered hierarchies, power dynamics and heteronormativity (Austin et al., 2003; Harbin, Beagan and Goldberg, 2012; Hovey and Paul, 2007; Watson, 2012).

Despite the potential of institutionalized health care to objectify persons, nursing education focuses, in part, on holistic care—treating persons in ways that attend to their biological, social, cultural, spiritual, and psychological well-being. (Beagan, Fredericks, and Goldberg, 2012). The very idea that we treat individual as unique is highly problematic, particularly as it often denies their social history, and when a patient is a member of a marginalized community, it makes them basically invisible. For example, if you are queer, of African descent, immigrant, etc., each member of those groups have experiences discrimination and to suggest this is not part of their social history is to ignore a significant part of who they are. If they are each unique, you are in danger of denying part of their cultural DNA sort of speak (2012).

Bioethicists have argued for increased awareness by healthcare professionals and institutions in relation to healthcare needs of individuals identified to belong to marginalized or oppressed groups within our society. Patients identified as members of marginalized groups have been shown to have less access to quality healthcare; be in greater danger of being misdiagnosed or blatantly dismissed by healthcare professionals and institutions (Baylis, Kenny, and Sherwin, 2008; Fowler et al., 2009). Santos Salas (2013) refers to this behavior as social exclusion. To combat the possibility of discrimination against marginalized patients, Canadian medical schools and the Canadian Nurses Association (CAN) have increased their requirements for cultural competency training (CNA, 2010; Reitmanova 2011).

Thus to be addressed by name and not be reduced to a room number or diagnosis is a fundamental of holistic and non-objectified care. In doing so, nurses and other

healthcare professionals maintain patients' humanity and avoid reducing them to their illness (Buus, 2001; Halldorsdottir, 2008; Oberle and Hughes, 2001; Watson, 2007).

In reflecting on the ways in which nurses work to create holism in their care but are often challenged within the constraints of the institution, Sarah discussed the following:

> He [patient] was such a lovely old man. But he wanted you there with him all the time. Just to talk, and boy could he talk. And every time I had to leave he would just slump down. I knew he was scared; he had told me countless times before that he was afraid. I was in such a hurry… I know it's no excuse, but we were working short that day, I mean really short we were missing two nurses, and that's crazy. I mean I had six patients [AND] I was giving palliative chemo to another patient. And that patient needed so much monitoring… I just brushed him [patient] off. I kept telling him to cheer up.

> Sarah looks ashamed as she lowers her gaze and continues:

> I still think about this poor man. I wished I could have gone back and done it all over again. But we [unit] were so short. He didn't understand this. All he understood was that I didn't have time to spend with him. He believed I didn't *want* to spend time with him. Sarah is now teary-eyed as she goes on: I never really got back the relationship we had built. I truly think it's because I let him down that day. He was unable to comprehend the reasons for it… but that shouldn't have happened. To this day, I try not to have something like this happen again.

Unfortunately, Sarah's obvious distress and anguish is common among frontline nurses practicing at the bedside within the confinement of institutional constraints. Feeling powerless and guilty over having to adjust their commitment to care not according to their patients' needs, rather to what those in power' deem practical or effective enough at the time (Austin et al., 2003; Austin et al., 2005; Cameron, 2004; Santos Salas and Cameron, 2010). Honesty, being present, willing and capable of gently guiding patients and their family members to redefine their vision of hope is an essential element of palliative care nursing. Allowing them time and space to grasp the notion that having hope does not equate with delusions of cure, but rather in finding the beauty in the everyday obtainable. (Ellershaw and Ward, 2003; Hebert, Schulz, Copeland and Arnold, 2009; Larkin, 2009).

Finding Hope In Midst Of Despair

Chiara contemplated the meaning of hope as she stated:

Hope can mean maybe not feeling nauseated that day, maybe hope the next day can be not in pain, maybe hope will be for that grandmother to see her grandbaby get born, maybe hope is surviving another three weeks so they can make it to their spouse's birthday. You know, there are still lots of milestones and lots of stuff, just because they are in palliative care that they still need to experience. Right? So I kind of look at it that way.

Sarah also discussed how she and the other nurses on the unit have celebrated and been part of many ceremonies and milestones honouring their patients. She commented:

Wow! we have had so many weddings, right at the bedside. I think it's like tying up loose ends you know? Like making sure everything will be taken care of legally… I mean not all are done for that reason, of course, but some. Like last year, I had this old woman that was dying. She had a boyfriend, and they had met at the retirement home. She had told me how he was constantly proposing to her, and she always said NO. Until she was admitted for palliation, and then she started to reflect on what mattered to her [Sarah smiles] and she said she realized she wanted to be married when she died. So, we had a wedding. It was summer, and the patio was open and pretty and their families came and decorated it beautifully. It was so lovely to watch. And Dr. Steve [pseudonym] moved the piano out there and played it during and after the ceremony.

Chiara also talked about how the patio had been used for many celebrations over the years:

I remember last summer when Dr. Steve held a concert for all the staff, patients and their families out there. I think we even posted it to YouTube [Chiara laughs]. But this one patient… I remember that I had brought his outside in his bed to listen to the music. His wife was with him, and she was so happy and sang along with the others, but her husband [patient] showed no reaction at all. Nothing! I could have just as well left him in the elevator that's how much emotion he showed. I don't know maybe I shouldn't have assumed that everybody wants to go outside and listen to music when they are this sick. I just remember how disappointed I was in his reaction.

In support of Chiara, this apathy is a known phenomenon. Patients experiencing unresolved symptoms, psychosocial withdrawal or apparent lack of interest in any and all engagement with family and friends is a common prelude to death (Lawton, 2000). This can be exceptionally difficult for the family to face (Zahis and Lewis, 2010). Spouses or partners of a gravely ill patient in palliation often experience emotional distress and frustration at the inability to fix their current life circumstances and report being overwhelmed and unprepared for the challenges of the road ahead (2010).

Coming To Know - The Suffering Soul

Reed (1996) explains suffering as the experience of isolation; hopelessness; vulnerability and loss. She suggests that a person that is able to find hope and meaning in his or her suffering is capable of experiencing transcendence. The ability to make meaning or sense out of suffering offers a measure of control for the suffering person that otherwise is lost in the endless downward spiral of distress (Johns, 2004). Reed (2003) fittingly summarizes this when she states: "Suffering may evoke exploration of issues of existence, perspective, and meaning that can influence a patient's ability to accept, endure, and sometimes transform or overcome suffering."(p. 66).

Therefore nurses [which goal is to alleviate pain and suffering], and have established a personal, trusting relationship with their patient are in optimal position to facilitate this process (Carman et al., 2013; Cassell, 2009). Through interventions such as listening, being authentically present and bear witness to the patients suffering, creates a caring space that invites reflection on the suffering helping patients find meaning and sense of their illness and destined fate (Bowes, Tamlyn and Butler, 2002). Inward reflection is described by Johns (2004) as the essence of being human. Similarly, Rogers

(1970, 2008) claims humans are "pandimensional" intertwined with their environments and are capable of awareness that extends beyond physical and temporal dimensions of the world (1970, 2008).

Some patients believe that God is in control of the world, and their suffering may be a punishment or a spiritual test they need to endure in order for a miracle to occur or enter into paradise (Hauser, 2005). Others do not seek redemption through suffering; rather they strive to detach themselves from the suffering through meditation (Wright, 2005). Chiara recalled a caring encounter she shared with a very young man and his family during the last two days of his life.

> The first thing I noticed was how big and tall he was. He was huge, I mean a gigantic man in every sense and his poor feet hung at least a foot past the bed [she grins]. He had a long thick beard and bushy eyebrows, but his eyes… I will always remember those eyes. He had light blue eyes that just glittered. I had difficulties communicating with him as he was so weak and kept falling in and out of consciousness. But I was quickly able to engage with his wife and daughter that never left his side. What I found out was that he [patient] was pagan. He fiercely worshipped Odin and Thor and those Norse gods. He had runes in a bag on the bedside table and some peculiar symbols on the walls. I had no idea what this was… I mean was he a Viking? He was big enough to be one though. The day before he passed away, he was rather agitated and in trying to figure out what was wrong his wife told me that he [patient] didn't want to die here. Not that he was afraid of death… but that he was missing his sword. She [wife] looked a bit embarrassed and said that apparently in order to reach the Viking paradise

Valhalla, he needed to die in battle with his hands on his sword. She was shaking her head and said that she and their daughter were Christians and had no idea about any of this as her husband had kept his *Viking* stuff away from them.

Chiara stopped for a while and looked at me with amazement, a SWORD in his hands, how in the world would that be possible? She chuckled before continuing:

I thought this was all a bit crazy at first. But I spoke to our chaplain, and he found this very interesting. And pointed out that he [patient] was already in the battle of his life. That he should be able to enter Valhalla without any problems. I hadn't looked at it that way before… but I guess it's a battle for sure. But the sword was another matter. I knew they wouldn't be allowed to bring one in. But I told his wife that if she would bring it well covered up, I would kind of look the other way [laughs] I mean it's a sword!

Chiara's story is the embodiment of how caring nurses are willing to go the *extra mile* of sort in order to make their patients' hopes and wishes come true. She continued:

It just meant so much to them, how could I be a stickler for rules and say, like, no I'm sorry your husband will not enter paradise because it's against hospital rules to bring weapons to the unit. It's not like they would be swinging it or anything. The next afternoon he passed away peacefully. I went into the room to pronounce and for sure… under the covers he was holding a large *sword.* But he looked so peaceful, and his wife and daughter were so happy. They couldn't stop thanking me for doing this for them. She [wife] said that she could at least be glad that his wishes came through. That now he would be buried with his sword. She hoped

that I wouldn't get into trouble. I didn't because even though some of the nurses

and the chaplain knew we were allowing this it just never reached the managers or

occupational health or whatever. I mean we have to stick with our patients. Right?

In the context of institutional conformity and power over women nurses, Chiara's

actions could be perceived as rebellious and against the norm. Women nurses as Chiara,

have been oppressed and conditioned to follow and adhere to the heteronomy,

contributing to their relatively disempowered status within the current healthcare system

(Goldberg, 2003). Nightingale (1861), regarded obedience to be a desirable female

[*nurses*] virtue and appraised nurses' for their submission to the authority of male

doctors, she stated: "It is recognized as the knowledge which everyone ought to have

distinct from medical knowledge, which *only* a profession can have" (p. 5).

This family depended on Chiara's agency; they needed her to reject institutional

regulations and make the autonomous decision to support them in the aforementioned

endeavour. She [Chiara] knew she ran risk of denying him [patient] his ultimate and final

wish. As Benner (2000) suggested:

> "Nursing practice invites nurses to embody caring practices that meet, comfort,
>
> empower and advocate for vulnerable others. Such a practice requires a
>
> commitment to meeting and helping the other in ways that liberate and strengthen,
>
> and not ways that impose the will of the caregiver on the patient" (p. 11).

Regardless of *knowing* their loved one is terminally ill and dying; when the

patient deteriorates, family members as well as patients themselves, can and do

occasionally reject the notion of death (Kübler-Ross, 1997). Refusing to face one's own

mortality and deny the fact that death is inevitable makes death irrelevant which a well-known coping mechanism is used to protect oneself against the paralyzing fear of dying (Vess and Arndt, 2008). However, this mode of engagement where patients and their loved ones are *just-not-ready* to face the inevitability of death needs to be further explored. Lydia discussed a patient she attended in the last days of life:

> He was so incredibly calm. The way he talked it was obvious he just wasn't quite registering that this was happening to him. I mean he knew, the doctor had been up-front about what was happening, and he had seen the images of his tumour, so he knew exactly what his situation was. But it just… I mean the way he talked it was like, yea when this is done I'd love to travel some more, or, I'm planning a cruise after the New Year.

> Mok and colleagues (2010) remind us that the dying patient is vulnerable and often terrified of the absolute finality of death. Noted by Callahan (2011), for some patients' and or family members, death is never an option. This can be detrimental if paired with similarly minded healthcare team where any and all treatments are sought regardless of the risk of dire ramifications, and death is personified as the evil thief of human existence.

> As discussed by the nurse participants above, finding hope and purpose in the seemingly mundane tasks of everyday life can assist the dying patient by reframing their goals (Fillion, Dupuis, Tremblay, DeGrace and Breitbart, 2006; Sand, Olsson, and Strang, 2009; Sullivan, 2003). However, this does not hold true for everyone, as Aria stated:

Sometimes, no matter how much time you spend talking to a patient or his family, they just aren't ready to face the hard facts. Those are the patients that will be a full code until they pass. They miss out on getting excellent palliation because they just believe so strongly that false hope is better than no hope. They just don't want to die… I mean I get it. Who can blame them?

All the nurse participants felt that their own hope for their patients and families was the hope for a peaceful, quick and painless death. Chrystal commented:

It is so awful having to watch the one you love suffering an agonizingly slow death. It becomes such a struggle for the family. I mean they don't to lose their loved one… but they still kind of want them to die because this struggling is just too difficult. For all of them. … But you have to look at it as they're going to a better place, they won't be in pain anymore, they won't have to go through any more treatments. …We try to change their outlook on…well sort of on *death* to try to help them be ok with it somehow like come to terms with dying. I know it sounds strange, but, death is definitely not the worst that we see in palliative care. Oh no, death can truly be a positive occasion. Usually, the patient has already made peace with death when the time gets closer. It can just be very difficult to get the family to accept it as well.

Conclusion

In this chapter, I discussed the theme, *"Coming to Know in the Nurse's Engagement of Hope in Palliation."* By way of analyzing the participant narratives and my own observational data, I stressed the importance *hope* has within the palliative care space. One cannot begin to engage through hope without first *coming to know.* This

suggests discovering who the person is who shares in the space you are working in *removed* from the disease that preys upon his body. Only then can nurses begin to foster and maintain their patient's hope through relational engagement and the art of caring acts. I address how people faced with the grim knowing that their final days are upon them, occasionally retreat inwards away from those that love them. How through exuberant kindness, the simple act of serving tea and cookies can instil hope and happiness in all that bear witness. Hope is to have a purpose, and the courage to live life without being defined by ones' diseased body. The nurse participants truly strive to keep hope alive, through the transcendent journey towards death.

Chapter   V

Stereotypes And Generalizations Of Gender And Caring: Moving Beyond Our Historical Legacy.

Once we consider nursing and medicine as paradigm cases for the change in western culture, and see them release the hierarchical frameworks and practices that automatically rank one person, one profession, one race and one gender over another, then we can be free to see again (Watson, 1999, p. 55).

In this chapter, I illuminate the gendered experiences of the nurses in the study, and the ways in which they have been culturally constructed within the historically gendered (female) narrative of the profession. This narrative is one that has been problematized because it has been situated in a health care context that has systematically devalued and diminished interpretations of women's work (Drachman, 1983; Henly and Moss, 2007). However, there is a renewed understanding of caring work (Leininger, 1981; Watson, 2008, 2012), and the nurse participants in this study further illuminate this valuing of care through their storied experiences in the context of palliation. Further, as more men enter the nursing profession and challenge gendered stereotyping, and discrimination (Evans, 2002), broader interpretations of care have evolved, moving it beyond its feminized origins as solely women's work.

To care from this broader and critical perspective entails an embodied engagement on the part of *all* nurses, independent of their gender identity to create holistic and healing spaces grounded in trust, mutuality, and respect (Evans, 2002).This chapter thus illuminates the experiences of women nurses in their caring work during

palliation and the ways in which they understood this work as gendered and the implications for care.

Caring: The Heart Of Palliation

Individuals choose to enter the nursing profession for various reasons (Cho, Jung, and Jang, 2010). These include a desire to care for others, an interest in the health professions, a desire to travel, and/or an assurance for job security (Miers, Rickaby, and Pollard, 2007; Mooney, Glacken, and O'Brien, 2008). While the nurses' reasons for entering the profession were not dissimilar from the evidence, the breadth and depth of their responses were not only heartfelt but also inspirational. For example, Brianna stated the following about working in palliative care:

> Palliative care is where I belong, where my heart is embedded. To love and care for each beautiful individual as they journey the magnificent path of the unknown, towards death…and beyond… This gift, to be able to bear witness to the release of suffering is precisely why I was drawn towards this vocation to begin with.

These words, so eloquently spoken by Brianna, exemplify the passion, love and altruistic ideals of nurses that have deep love for their practice (Beck, 2000; Cook, Gilmer, and Bess, 2003; Goldberg, 2005; Watson, 1999). Similar to Brianna, Watson (2003), reminds us of the importance of recognizing the meaning of our own practices when working so intimately with others. Thus Watson stated:

> When working with others during times of despair, vulnerability, and unknowns, we are challenged to learn again, to re-examine our own meaning of life and death. As we do so, we engage in a more authentic process to cultivate and sustain

caring-healing practices for self and others. Such care and practices elicit and call

upon profound wisdom and understanding, beyond knowledge, that touch and

draw upon the human heart and soul (pp. 197-198).

Being a palliative care nurse not only requires the practical skills of nursing, but

also the artful attention and interpersonal skills that enable relational caring attributes

resulting in the formation of trust needed to establish an embodied relationship (Bergum,

2003; Benner, 2000; Goldberg, 2003, 2005, 2008; Larkin, 2010; Watson, 1999, 2003,

2012). The humanistic and compassionate ideals that enable one to enter another's space,

and be authentically present at some of the most difficult and heartbreaking moment in

patients' lives can be both exhilarating, yet profoundly draining for the nurse. As

Chrystal, one of the nurses stated:

> Being a palliative nurse is very different from any other nursing I have done. You
>
> constantly have to give of yourself. It is not an easy job... not at all. I mean it can
>
> be difficult and hard in different ways, both physically and emotionally. It´s like
>
> being on an emotional roller coaster; on one hand it's completely draining and
>
> upsetting yet at the same time it's also fulfilling and exciting.

Chrystal's comments were echoed by all the nurse participants in the study.

Furthermore, these experiences of conflicting emotions are common amongst nurses that

practice within the palliative care settings (Rasmussen, Sandman, and Norberg, 1997). As

Sarah commented: "I can easily go from being extremely happy over a discharge in the

morning, to crying my eyes out in the stock room at noon. You just never know what is

going to happen each day as you come in." Aria, one of the nurse participants, has been a

dedicated palliative care nurse from the start of her long career. She explained:

My very first consolidation, I got placed on the old palliative unit at Southlake. I

didn't want to go there because it was the darkest, dingiest, creepiest place you've

ever been in your whole life. My first day, two people died. And I thought there's

no way I'm going to do palliative care; people are dying all over the place and its

nothing but sadness. But no... To my surprise, at the end of the week, I knew this

was it; this is where I belonged. I went to my preceptor and said, "I know we've

got more consolidations to do, but I won't do them anywhere except in palliative

care."You either love it, or you hate it….And there is no middle ground in this

kind of nursing. You can't have middle ground.

Smiling, Aria continued:

It was all because of the nurses…these two nurses that are now retired. I had

absolutely the best time, and not in the sense of being fun, but oh-my-God, I

learned so much from these two women. It was just like I went home at the end of

every day and I felt like my head was going to explode, they kept on constantly

pounding this stuff into me, how to treat people, how to be compassionate, how to

care…

Aria strongly believed that those two nurses influenced her decision to become a

palliative nurse. She stated: "They just knew how to do their job so well, how to be with

people, how to treat people, how to teach me how to treat people."It is well established

that student nurses are often heavily influenced by their clinical educators during their

clinical placements, as positive experiences during the student journey set the tone for

future practice (Benner, 1984; Randle, 2003; Ryan et al., 2010).

Insofar as the act of nursing has historically been viewed as an extension of woman's caring, mothering and being the physician's handmaiden (Anthony, 2006; Gordon, 2005; Henly and Moss, 2007), gender has deeply influenced the profession. Nursing has been challenged to gain status and respect within the biomedical paradigm, resulting in a deliberate movement away from its more feminized historical beginnings (Benner, Sutphen, Leonard, and Day, 2010; Gordon, 2006). With the acclimation of science, technology and baccalaureate preparation for entrance to nursing practice, the move away from caring gained further incentive as science reigned supreme (Drachman, 1983; Benner et al., 2010). However, with a recent shift in educational curricula, there has been a renewed interest in the relevance of the human and caring sciences to practice (Porr, 2009; Purnell, 2009; Watson, 2003, 2012). Thus the valuing of multiple forms of knowledge (i.e. aesthetic, empiric, political, ethical, spiritual, cultural…) has been re-considered as relevant to best practices (Carper, 1997; Watson, 2008; White, 1995). In so doing, the artistry of caring becomes essential the practices of *all* nurses, jettisoning the claim that it is solely women's work (Cudé and Winfrey, 2007; Goldberg, 2003; Porter, 2008). However, as evident by the nurse participant narratives; palliative care has served to reclaim the place of emotions and caring in health care practice, and the profession of nursing continues to attract individuals that embody a fundamental desire to provide care to another (Watson, 2003).

When reflecting on the artistry of caring, and how it came to be integrated into Chrystal's life, she commented on the experience of her grandmother dying alone. Thus she stated:

I think why I love nursing, and especially palliative care is probably based on my personality and experience. Well, honestly, I love palliative care but I do think my love for it and why I think families are so important is based on when my grandmother died, and I just felt like there was no one was there with her. She died alone, all alone. I was very young, and I wasn't with her. She died in the middle of the night, and I've always wondered what happened. I wished someone that really cared about her could have been with her. That's what so important to me…that nobody dies alone.

Similar to Chrystal, Lydia considered whether or not her love for nursing and especially palliative care, was related directly to her own personal heartbreaking experience as an eleven-year-old little girl as she had lost her 34-year-old mother to breast cancer. She noted:

I guess in some ways I can put myself in certain positions. Like when there's children involved. I think it comes back to my childhood. I think it comes back to losing my mom so young to cancer. I can't even believe I'm nursing in cancer; I really don't know why--not why I'm here, but how I got here, based on what I've experienced with it…I think it's my childhood experiences and my growing up and having to fend for myself independently.

Lydia had trouble discussing her childhood trauma any further. I offered to stop this line of dialog and offered her water and tissues. She was deeply troubled by the recollection as it stirred up difficult unresolved childhood memories for her. While wiping her eyes, she absently stated:

I said to one family, the daughter was eleven, and I said, "Watch her, and make sure you watch her." Because I remember me, and I remember what I went through, how I didn't know anything, how no one told me anything, how I woke up to have no mother one day…and I think it comes into my nursing as well.

The genuine *need* or *want* to care for others has shown to be the strongest suggested indicator of why individuals chose to pursue the nursing profession (Cho, Jung, and Jang, 2010; McCabe, Nowak, and Mullen, 2005). Angela commented that she had known she wanted to become a nurse from the age of five. She explained, "I think it's the helping people, you know. Some days it's harder than others, but I really think it's just the fact that you're helping people when they can't help themselves when they are at their worst." In agreement with Angela, Brianna continued to be poetic in her description of her inherent love for palliative care and the need to be with and assist her patients in with care:

> There is nothing that comes even close to describing the depth and magnitude of the love I feel rushing through my veins as I tend to a dying person. To be given the privilege of laying my hands on them, to soothe a troubled soul or a broken heart. As this person, this unfortunate human being accepts their fate. And I listen to them reminisce about their lives, what they achieved what they didn't. They tell me about their travels and their families as well they tell me of all their future hopes and dreams that now are gone. I sit with them as they write instructions for their funeral… or the toast for their daughter's wedding. I help them write birthday cards and holiday cards for the years to come. They cry, and I cry… it's

a connection with one's soul. And I get to be with them when they leave this world. It's pure and comes from love. That's why I love nursing.

The inherent need to care for another has been normalized as a feminine attribute since the dawn of civilisation (Henly and Moss, 2007). By caring for their family, homes, and community, women were generally regarded as natural nurturers and healers (2007). Therefore tending the old and caring for the suffering became a natural extension of the female role (Henly and Moss, 2007; Leacock, 1981).

The eloquent narratives of the aforementioned participants illuminate, in part, a depth of care for patients and families drawn from childhood experiences. This has entailed a need and desire by participants to embody spaces that provide compassion, care and kindness to others. However, this work, as previously noted, has historically been devalued and lacking in credibility because of its gendered and feminized nature associated with women's work (Brennan, 2005; Lloyd, 2002). Nevertheless, current practice offers opportunity to transform this narrative and shift our understanding of caring as solely gendered. As Watson (2012) so beautifully articulates:

> For nursing to be truly responsive to the needs of society and make contributions that are consistent with its roots and early origins, both the nursing education and healthcare delivery system need to be based on human values and concern for the welfare of others. Caring outcomes in practice, research, and theory depend on the teaching of a caring ethic, a philosophical orientation toward honouring the whole person and all of humanity, along with knowledge and skills of caring both in one's ways of being as well as in practicing and living out caring modalities, all based on a caring science orientation toward professional practice (p. 42).

Collegial Support Through Caring.

Palliative care nursing is, by its intimate and complex nature, a challenging profession that calls for a supportive working environment. It requires colleagues that understand and value everyone's differences, similarities, strengths' and weaknesses in the context of palliation and caring (Georges, Grypdonck and De Casterle, 2002). It was evident from the storied narratives and observational shifts that the palliative care unit includes nurses that both value and practice authentic teamwork. As Angela described: "The team is really good...We work as a team. It's not so much the individual, this is me, and this is my patient and all that stuff, you work as a team." But teamwork is more than collaboration in palliative care, it requires something profound. As Watson so beautifully stated (2003).

> When working with others during times of despair, vulnerability, and unknowns, we are challenged to learn again, to re-examine our own meaning of life and death. As we do so, we engage in a more authentic process to cultivate and sustain caring-healing practices for self and others (p. 198).

While the nurses are accustomed to caring for strangers, they were also accustomed to caring for their own. They had experienced a loss of one of their own more than once. As Chrystal explained:

> We are a relatively small hospital, I mean you could always go to Toronto for treatment, but this is close to our homes. It's really difficult to take care of one of our own although we do and have done so multiple times. I mean it's so hard because you kind of put yourself in their shoes, right? It could be me one day. I

remember a while back, a nurse that worked on [different floor], and one day there was a code blue, and apparently she just collapsed at work. She had all these tests done and ended up on our unit a few days later with aggressive [cancer]. We all claimed ownership of her [smiles], we held fundraisers for her family, and all of us pitched in what we could. We took turns looking after her and just being with her. Chiara stopped and looked deep in thought before continuing: Did she [patient] get special treatment… well, yes…and no. I mean of course in a sense because she was one of us. But… I mean everyone gets the same quality of care, but I guess if you look at it… well… yes, I can see how we don't fundraise for every patient [chuckles] that wouldn't be possible. But she [patient] was one of our own. We have had too many of our own on our unit as patients, and every time we kind of make sure we go that extra mile. We fundraised for their families; bring in stuff from home to give them and that kind of stuff. I mean that's the least we can do. Right?

During my observational shifts, I observed how close-knit and in sync the palliative care nurses seemed to be. The nurses, although centered around the nurses' station, never ignored a call bell from a patient that was not assigned to them, or refused to assist a family member of an unknown patient. When, for example, the unit became very busy, the nurses seemed to function like a well-coordinated orchestra. No one asked in frustration for assistance; it was given without hesitation or questions. It was beautiful to watch how in-step with each other the nurses worked, side by side, lending their hands and their bodies to those that needed an extra pair. Conversations flowed from personal stories to hospital staff to patients and their families. It became quite apparent that these

women had practiced side by side for a long time. They had emerged as a group that respected and supported each other, shared responsibilities, laughed together and vented their frustrations to each other.

Ryan and colleagues (2010) suggested that "collegiality, respect, openness to ideas and believing in others are key to supporting nurses in practice." (p. 188). Caring was central in the nurses' interactions with each other during my observations; they displayed unity, respect, compassion, and support for one another. Their sense of integrity appeared to be entwined with an ethic of care so that to see themselves as *good* nurses, was to see themselves in a relationship of connection with others (Watson, 2003). As Cloyes (2002) commented: "Caring has repeatedly been described as not only the foundation of what nurses do, but of who nurses are" (p. 203).

Even Barbara, one of the nurses discussed in the previous chapter who initially may have come across as "matter of fact" in her provision of care, participated in conversations with colleagues and assisted other nurses with caring activities. Barbara's "matter of fact" behaviour, while possibly indicative of her general disposition, may also be a product of her educational context within the nursing profession. As noted by Brennan (2005), "Unfortunately, nursing has developed within an altruistic domain, set up to carry out physician's orders and connected to "an ethos, which rotated around principles of duty, order, and obedience" (p. 283). This school of thought was to give credence to nursing tasks firmly embedded within the biomedicine paradigm. This focus aimed at prioritizing the problems at hand and systematically and efficiently work towards solving them.

Not dissimilar from the findings of Brennan (2005), Brianna, one of the nurses offered the following explanation, as she nears the age of retirement:

This was just a totally different time; you kept yourself protected by keeping a brick wall around your heart and emotions. We were strongly discouraged from becoming too close with our patients, yet alone their families. That was considered to be the proper professional behaviour and those of us who never could stop ourselves from becoming too involved with our patients, were made to feel inferior nurses [laughter]. Interestingly enough, my patients used to tell me I was their favourite nurse all the time so I didn't change. I don't think I could have. Being distant just isn't me. But then I got into trouble on many occasion [laughter], my uniform wasn't pressed well enough, and my cap had tendencies to fall off at the most awkward moments… a few times during morning rounds right in front of the matron. The older sisters and the matron used to tell us young ones that even if we weren't proper nurses yet; we at least were expected to look like we were. Brianna laughed as she reminisced and sipped her tea before she continued: It was so different back then, nowadays you cannot distinguish the nurse from the service attendant or pharmacist as everyone is wearing similar clothing.

In retrospect, Barbara's actions were reflected in Brianna's words. Her bodily stance, her demeanour and perceived apathy, might instead best be viewed in the context of how and when Barbara was *trained* as a nurse as well as her lived experience as a young woman during times when subservience to [male] authority was unquestioned, just before the dawn of the feminist movement. Lloyd described the following (2002):

They wore their cap, school pin, and name tag in an ordained manner. Nurses

were to maintain a certain demeanour and propriety. Nurses did not call each

other by first names when on duty, even if they were best friends and out of

earshot of patients or other staff. They were taught to keep a professional

distance, not to become emotionally involved so that they could maintain their

professional judgement and performance (p. 110).

The holistic approach to patient care and nursing practice advocated by the

professional nurse scholars of today is far removed from the rigid and formal norms of

previous times (Golberg, 2005, 2008; Halldorsdottir, 2008; Larkin, 2009; Rogers, 1970;

Watson, 1999, 2003, 2008). A caring nursing practice cannot be understood and

described as a set of structured behaviors or nursing tasks. Rather, rooted in the ethical

frameworks of caring, relationality, and embodied practices it emphasizes

interconnectedness in the context of trust, thus, collaborating with patients to be active

and vocal partners rather than passive recipients of care (Bergum, 2003; Benner, 2000;

Goldberg, 2003, 2005, 2008; Watson 1990, 2003).

Gender (Mis)Interpretations: The Trouble With Binaries And Dichotomies.

While our sex is determined by biology, our gender is determined by culture and

social construct. As such; gender and gendered issues are infused into every aspect of

human existence, including nursing practice, whether nurses are consciously aware of

this issues or not (Young, 1990). Anthony (2004) suggested that nursing students are

inundated with gender bias from the beginning of their nursing education, attributed to

the predominately female nursing faculty, lack of male nurse role models, and the

consistent use of gendered language in nursing textbooks. Grady, Stewardson and Hall

(2008) concurred in that the nursing profession continues to be laden with a feminized discourse that perpetuates the gendered stereotype –as, *she* cares, *she* the nurse, *she* is kind and compassionate, arguing a dissonance between the current reality and the hopes of a gender-neutral profession (2008). Sarah commented:

> Women are just more caring. From the time they are little girls. …Well, I don't think it comes from being a mom or anything, I mean I don't have kids yet, but I still feel that I have that thing. That female gene that just makes me a great nurse and I think it comes from being a woman. I'm not saying men aren't great nurses. Not at all. I'm just saying that it's some kind of sensitivity or nurturing that women have that most men don't have. I think men are more task oriented than women. I think a fast paced environment suits them better not maybe palliative care or labour and delivery. You know. I mean there are wonderful male nurses out there. They are just a little bit different than women nurses. I cannot point my finger on it.

Chiara concurred with the belief that caregiving was part of a woman's genetic makeup. She stated:

> I mean even if you look across cultures all over the world for hundreds of years, women have generally been the caregivers of children, of their husbands, of their parents or whatever. I think men are more cut and dry, to be honest with you. I think culture and how you're raised moulds who you are.

> I think…maybe my perception is that maybe patients and families have automatically more of a trust…they have more trust in regards to having a woman

nurse than a man nurse. I just think it because generally maybe women are more open or easy to talk to, they're more…they're more of talkers, they're more listeners, and they're more…. Then you see…some patients, you know, they're not comfortable with male nurses. I wouldn't be comfortable with a male nurse at my age.

Sarah echoed Chiara's opinion when she said: I wouldn't be ok with a male nurse myself. I mean it would be ok if they were just hanging a med or such… but I just wouldn't be comfortable with a male nurse doing a bed bath or changing me or anything like that. I would just want a female nurse. That's all.

Chiara believed she was traumatized as a young girl which influenced her feelings towards male nurses still to this day. As she stated:

I broke my arm, and I was very young. I was very developed, and the orthopaedic surgeon took my shirt off. I was horrified, more due to that than the pain; but that I was exposed to this man I don't even know…Chiara shook her head in remembering. So I've always had female doctor since…I mean, when it comes to very personal things… I'd just want a woman. I mean there are many patients both men and women that don't want a male nurse to take care of them.

Anthony (2006) credits Nightingale with the foundation of the myth of the feminine nurse, in which it was *natural* for women to be nurses, and conversely, *unnatural* for men (p. 44). Ongoing gender bias within nursing has been identified as a significant contributory component in explaining why men nurses leave the profession in high numbers within the first four years of practice (Anthony, 2004; Evans and Frank,

2003). This has resulted in a negative cycle of recruitment, retention, and subsequently resignation, of men nurses at such time the profession struggles to surpass the gendered stereotype, historically assigned to nursing (Rhodes, Morris and Lazenby, 2011).

Not surprisingly, given the aforementioned narratives, the nurse participants agreed that on those occasions a male nurse had floated (taken an extra shift) to their floor, many of their patients had objected to have them as their nurse. Angela discussed how hard it can be for nurses who are men to practice within this culture where men are supposed to be doctors and not nurses. Such culture reinforces the binary of masculine/feminine, thus posing significant harm to all nurses, independent of their gender/gender identity. Angela described these challenges further with reference to the generation gap and the ways in which they are perpetuating stereotypes:

> She commented: The older generation has hard time seeing men as nurses. I mean we have had male nurses pick up shifts on the unit, and they have had problems with people that are refusing to have a male nurse, they absolutely don't want one. They might say; I don't want a male nurse, they are not supposed to be nurses. But that's the way that they were brought up. Right? It's an older generation that's coming into the hospital these days. Men are supposed to be working and all that kind of stuff, just not as a nurse, that's a female job, and if men wanted to be in healthcare, they should have been a doctor and that kind of thing. It's just the way that they think. I've had a lot of men that say "I don't want him, he shouldn't be doing this", and then it's "are they gay and is that the only reason why they're here", or "were they not smart enough", or "should they be a nurse if they weren't smart enough to be a doctor."

Lack of acceptance of men nurses by other nurses who are women are believed to contribute greatly to the perceived discrimination men nurses experience in the workplace (McMillian, Morgan, and Ament, 2006). Affinity for caring and the ethics of care in the context of nursing practice are not an exclusive feminine trait, as men also exhibit strong tendencies to care (Cudé and Winfrey, 2007; Evans, 2002; MacDougall 1997). As apparent from the participant narratives, men nurses have been accused of not being as caring and compassionate as women nurses. A study by Whittock and Leonard (2003) concluded that men believe they have all the same caring attributes as their female counterparts. However, men nurses felt that women nurses questioned their caring abilities based solely on their gender. This in turn made them question their profession and professional, caring abilities.

Angela, who was one of the younger nurse participants, and the only participant that would not object to have a male nurse attend her, became clearly upset as she discussed the apparent discrimination against men nurses. She commented:

Especially around the male population that's in the hospital, they [male nurses] have a hard time being accepted. You can also see that they get their backs up a little against it because they still went to school; they are no different than we are—there is no difference between me and a male nurse. But it's all gender-based, and it sucks because they are no different. They have the same learning experiences, but because some men don't think that it's good enough, they are told that they should be more than a nurse. I would be perfectly fine with having a male nurse; a nurse is a nurse is a nurse… Right?

According to Okrainec (1994), male nurses have experienced role strain from working in a historically female profession. This has resulted in men gravitating to more gender appropriate and masculine areas of healthcare such as mental health and management. Trossman (2003) stated, "There's no question about the public's stereotype of a nurse: white cap, unquestioningly following doctors' orders –and female" (p. 65). Her statement illuminates the much gendered image of nurses. Evans (2002) suggested that men nurses who practice at the bedside frequently encounter discrimination due to their gender often laced with suspicion of a sexual nature and mistrust on the part of both patients and colleagues. That all intimate, caring acts, touching and hugging which are gratefully accepted and appreciated if given by woman nurses, somehow become open to sinister misinterpretation when the nurse giving the care is a man (Evans, 2002). Despite Evan's research being over a decade, her findings continue to be relevant to current practice. Gender stereotyping and discrimination continues today. Hence, significant work remains to address these issues of inequity to create healthy work environments for all nurses.

Within the gendered institution of nursing, men nurses are culturally expected to choose management and leadership roles *above* bedside nursing as leadership roles allow for assertiveness and other behaviours that are accepted attributes of masculinity (Connell, 2002, Kimmel, 2000). It has also been stipulated that men nurses have a smooth ride up the corporate healthcare ladder due to their sex and historical norms (Evans, 1997). Men nurses have also been found at greater risk of leaving the nursing profession completely due to dissatisfaction with the organisation, lack of respect, lack of support and low pay (Evans and Frank, 2003; Rajapaksa and Rothstein, 2009).

As nurses already equipped with the science and the technology of current modern practice return to the basic form of the caring role, it has to be understood that it is not solely in a context of women's work, but caring as a critical form of health and healing is for *all* nurses to embody as fundamental to care (Goldberg, 2003, 2005; Ryan et al,. 2010; Watson, 2003, 2012). Determination and movement aimed to surpass the historical gendered identity of the profession of nursing can only be accomplished by moving beyond that of traditional female embodiment (Evans, 1997; Evans and Frank, 2003; Goldberg, Harbin, and Campbell, 2011). In the words of nurse participant Brianna, as we finished one of our conversations relating to issues of gender and nursing, as she was deep in thought, she stated: "What a complicated state of affairs."

Gendered Perceptions Of Power And Oppression

The nurse participants discussed how distressed they had felt when faced with a situation where they felt helpless or powerless in managing themselves. Circumstances, where the nurses' own worldviews on gender equity and women's rights, are in opposition to the patient and family can have a detrimental effect on establishing a relational caring relationship. Young (1990) stated, "all oppressed people suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts, and feelings" (p. 4). Nevertheless, knowledge informs the provision of care, and as such culturally congruent care aids in the elimination of inequities and stereotyping of patients and families from cultural backgrounds that differs from ones' own (Borkan and Neher, 1991).

Young's words can be illuminated in Chiara's narrative:

I got ethics involved because I was starting to have difficulty dealing with the way he was dealing with her. And I knew there had to be some sort of way to deal with it before my nursing cap came off and my…temper blew. But then it's cultural, I understand that….Because I want to say to them; your wife is not property, you can't talk to her like that, you can't treat her like that. You're not allowed to here in Canada…but really? Can we talk to family members like that? I didn't want to get into trouble so I called ethics down.

This patients' cultural background was apparently firmly rooted within a society that defines gender roles in such a way that Chiara felt justified in getting another party involved. However, according to Al-Shah, Ayash, Pharaon and Gany (2008), without culturally informed knowledge, there are inherent dangers in the stereotypical presumptions often ascribed to persons from patriarchal cultures and in particular, people of the Muslim faith.

Johnson (2005) wrote: A society is patriarchal to the degree that it promotes male privilege by being male dominated, male identified and male centered. It is also organized around an obsession with control and involves as one of its aspects the oppression of women (p. 5).

In situations where social, cultural or even religious norms restrict woman's freedom to make any decisions regarding her own body or the care of that body and submissively accepts her role as *lesser*. French (1993) argues that "women were the first slaves" (p. 9). A fitting description that sadly still holds true for millions of girls and women in many parts of the world today. Where adult women still do not have power and control over their own bodies, their

marriages, their sexualities, or their children. Where women are unable to move around freely without a male relative to escort them, to dominate them, to rule them. Where young girls are maimed or killed for demanding a basic education, a profession, a life and freedom (Hamdan, 2005)

Nurses caring for women patients from patriarchal cultures need to find the courage to reject the oppressive hierarchy. As Santos Salas, (2013) stated, "the healthcare professional… as the producer of knowledge has the task to assist in deciphering the world of the oppressed to others and also to those in positions of power" (p. 176). Only by reclaiming the power and give it voice within the practice environment can nurses and patients have a genuine human-to-human relationship built on equality and respect (Butler, 1997; Goldberg, 2003). Institutions can have action plans and set policies that stipulate zero tolerance of any and all acts of discrimination, violence and abuse. However, unless nurses feel supported by their colleagues and leaders, chances are they are not empowered to file a complaint against set offender.

De Beauvoir (1989) stated, "One is not born, but rather becomes, a woman" (p. 273). While this can be a controversial claim by some scholars (Bergoffen, 1997), it nevertheless continues to have significant meaning. It takes courage for a girl to become a woman on her own terms that question the socio-cultural norms and expectations of society by further rejecting the objective gaze and disapproving patriarchy (Young, 1980, 2001).

Sarah described how dismissed she felt when trying to give relational care and establish a caring relationship with a patient and his family from a very strict Islamic background:

They questioned every nursing act I performed. And they were very suspicious. But that could have been because of their culture, and I was *just* a woman…I was a bit ticked off in the sense that we have these badges, we're nurses for a reason, I have gone to school for this, and I am good at what I do. Sometimes people act like we're just someone off the street, no matter what credentials we have…like when I told them about my education and all of my experience, it still didn't matter, and it was like talking to a brick wall. They still questioned my ability. I understand that they have a right to question me and have opinions, but when you give them advice, you know, when you tell them that in your nursing experience and your life experiences with patients', etc. They don't see that as relevant so they ignore what you just told them and will still question it. And so…and that's what I have to say to myself, I've done the best I can, I can't make them understand. But it's difficult to build a good relationship with them…basically, it becomes just tasks.

Sarah continued: "Often it's the husband or father of the patient that has to control everything. But that's if the patient is a woman. She cannot make any decisions by herself. And that's distressing to us."

Firmly rooted within the current patriarchal health care system are the challenges and issues of power and lack of power, especially for front-line nurses who are predominantly women (Butler, 1997). This is not to say Islamic cultures do not support women's rights. In its fundamental form, the Islamic religion supports not only women's rights but argues against oppression and injustice of any sort (Aranda, 2006; Nurdin, 2011). However, it is through historical and culturally constructed practices by men that

has resulted in the widely accepted disempowerment and inequalities of women and other marginalized groups within Islamic societies (Haideh, 2011). In western cultures, there are dangers of thoughtlessly stigmatising immigrant women from masculine cultures, as *all* having suffered injustice, oppression and abuse by the male dominated patriarchy (O'Mahony and Donnelly, 2010). This in turn can lead to unjust treatment, disrespect and discrimination by healthcare professionals against an entire cultural group.

Galanti (2000) argued that many nurses believe if they simply treat every patient with respect they will avert most cultural problems. However, as illustrated from the participant stories, this does not always hold true. In considering cultural differences, nurses are in danger of unwittingly stereotyping and displaying ethnocentric view of immigrants (2000). Moreover, making this generalised assumption further contributes to the marginalization and oppression of immigrant women by dismissing their lived embodied experiences (Marrone, 2008).

Self-reflection can assist nurses in identifying the values and biases that highlight his/her approach and interventions when faced with patients from different cultural backgrounds such as those previously mentioned. To examine their reactions to various situations in order to discover why they responded in a particular manner to a given patient. Moral distress amongst nurses has been widely studied by nurse scholars (Austin et al., 2003; Austin et al., 2005; Manara, Villa, and Moranda, 2014). Collectively it has been identified as a phenomenon in which one knows the right action to take but is constrained from taking it. The topic of moral distress among palliative care nurses will be discussed in greater detail in the next chapter.

Chiara discussed how demoralising it feels when her ability and knowledge is put into question because of her sex and or occupation. She commented:

I have tried so many times to tell them [doctors] what I think this or that patient needs, but most of them end up not listening and just do what they think best. It's really frustrating when you absolutely know that a patient needs different meds for the night, like I mean they are climbing out of bed at night, and the doctor doesn't give you anything to give them…. It's like they think you're lying. It's not like we are making this up, we all just want what's best for the patient. Right?

Chiara was visibly upset as she continued:

Once after a really, really bad night shift, I mean the patient wasn't mine but we all had to chip in and help because [nurse] was at her wits end. The patient hadn't slept a wink all night, was so restless and constantly trying to get out of bed. Well in the morning the doctor shows up and [nurse] tells him how the night shift had gone. And she suggested that he prescribed more pain meds, Haldol, and some Nozinan to keep her [patient] calm. We were all there…this was at shift change, so we all saw and heard what he [doctor] said. I mean he could have been in a crappy mood, but it's no excuse. He turned to her [nurse] and asked her if she had gone to medical school. She [nurse] got so flustered, her face became beet red. She told him NO she had not gone to medical school but that she knew this patient well, and she had been working here for quite a number of years, so she knew very well what the patient needed. And he just looked at her patronisingly, like she was nothing… like she didn't have the right to say any of this. Then he

said; "You are just a nurse, and until you have gone to medical school like I have for many years, you can't question my decisions."

And with that he just left… Just like that... Like he wasn't even bothered that all of us [nurses] were right there and could hear him talk to her [the nurse] in that way. And really we all took it as a personal insult, but what could we do? This is the way it is, right? I mean we couldn't go crying to the chief and say what? That he [the doctor] was disrespectful to us. No way, he would be on his [doctor] side for sure.

Unfortunately, Chiara's encounter was not unique. Within a hospital setting, physicians, medical students, as well as management, hold considerable power over frontline nurses. These oppressive power relations are often reinforced by a "culture of silence" (Friere, 1970, p. 29). As such, front-line nurses that *know* their patients, their families, and circumstances and have valuable opinions and thoughts regarding their patient care, often hold their tongue and follow the path the *power/decision* makers have decided (Kincheloe and McLaren, 2007).

Conclusion

Historically women have been demoralized as the lesser sex. They have been and continue to be objectified as the weaker sex, through accepted norms and masculine traditions (Gordon, 2005; Henly and Moss, 2007). McIntyre and McDonald (2014) stated:

To say that women are naturally caring suggests that all women are caring, just by "nature" of being women. This also implies that men are not (as) caring as

women. In reality, some women and some men in our culture are socialised to behave in caring ways. In addition, the "caring" that is involved in the caring relationship between a nurse and client is a "quality of relating" that is fully developed through nursing education, by nurses who are women and nurses who are men (p. 286).

However, with increased numbers of men graduating nursing school, nursing as a profession embarks on a journey to abolish the historical gendered stereotype of the female nurse (Meadus and Twomey, 2011), and embrace and position gender-neutral caring as the embodiment of all nurses, central to health and healing.

Many challenges face nurses in today's workplace, as the storied narratives of the nurse participants clearly reveal. The woman nurse perception of *self* is culturally and socially constructed through accepted norms and [often] masculine traditions of institutions. Unfortunately, our modern day healthcare system is still laden with gendered discrimination and oppressive power relations. The patriarchal hierarchy, still inherent within our healthcare system continues to demoralize and undervalue the importance of nurses, the profession of nursing and nursing practice. As evident by the participants' stories, different cultural backgrounds of patients and their families can be the source of significant challenge for nurses as they struggle to navigate the fine line between cultural sensitivity and ethical misconduct. Always placing their patient's best interest at the centre of care.

Chapter VI

From Empathy To Burnout And Back: Cultivating Self-Care Practices To Heal The Palliative Nurse

"Tears shed for another person are not a sign of weakness. They are a sign of a pure heart." (Harris, 2010, p. 13).

Palliative care, at its core, requires nurses to establish a mutual, trusting, and embodied caring relationship with their patients and families (Berry and Griffie, 2010; Duggleby and Wright, 2007; Halldorsdottir, 2008; Larkin, 2009, 2010; Santos Salas and Cameron, 2010). As gratifying as care provision for the palliative patient can be, the complexity with which care is delivered, ethically, physically, psychosocially, and spiritually, in tandem with the intimacy required can be challenging. Emotional distress has been documented as having significant impact on the health outcomes of palliative care nurses (Athlin, Furåker, Jansson, and Norberg, 1993; Bush, 2009; Keidel, 2002; Melvin, 2015; Sabo, 2006, 2008; Sinclair, and Hamill, 2007).

In what follows, the *potential cost of caring* is articulated through the nurses' stories of palliative care. Moreover, the nurses further illuminate the diverse and complex ways in which self- care practices allowed them to heal themselves when the emotional burden of caring became too much; despite their ongoing commitment to the provision of compassionate and competent care to patients and families. As previously discussed, nursing the vulnerable and dying patient is firmly rooted within the ethics of nursing practice (Canadian Nurses Association, 2008), yet it is not without the challenges of influencing nurses' physical, emotional, spiritual and psycho-social health and well-

being. The nurses in the study, despite being influenced by the *cost of caring*, recognized the core of nursing was in "caring" itself, and to ensure it remained fundamental to their practice, healing the *self* was instrumental, if they were to continue to support patients and families to the highest standard, grounded in compassion, respect, authenticity, and love, on their final journey toward death.

Caring Through Compassion And Empathy

Empathy is a human trait that entails the nurse being able to enter his/her patients' *world* and experience it through his/her eyes. Without judgement being able to comprehend what the patients' *body* is feeling and experiencing and being able to articulate that understanding back to the patient (Wiseman, 1996). Without empathy, nurses have difficulties establishing a meaningful therapeutic relationship with patients; as it is empathy that allows the nurse to immerse her/himself in the patient's subjective experiences which enhances the nurses understanding of the lived experience of the patient (Bennet, 1995; Walker and Alligood, 2001).

The multidimensional construct of empathy, however, and the ability to become overly empathic, thus consumed by the other's pain and suffering can leave one vulnerable to the effects of compassion fatigue (Melvin, 2015; Rourke, 2007). Indeed the Canadian Nurses Association (CNA) and the Registered Nurses' Association of Ontario (RNAO), (2010), remind us of the following:

> Nurse fatigue is a subjective feeling of tiredness (experienced by nurses) that is physically and mentally penetrative. It ranges from tiredness to exhaustion, creating an unrelenting overall condition that interferes with individuals' physical

and cognitive ability to function to their normal capacity. It is multidimensional in both its causes and manifestations; it is influenced by many factors: physiological (e.g., circadian rhythms), psychological (e.g., stress, alertness, sleepiness), behavioural (e.g., pattern of work, sleep habits) and environmental (e.g., work demand). Its experience involves some combination of features: physical (e.g., sleepiness) and psychological (e.g., compassion fatigue, emotional exhaustion). It may significantly interfere with functioning and may persist despite periods of rest (p. 2).

Secondary Traumatic Stress Disorder is another closely related term used to describe the physical and psychosocial manifestation of repeated exposure to traumatic events such as seriously ill and dying patients (Melvin, 2015). Angela, a nurse in this study, provided another way of understanding the experience in part of her narrative: "You almost take on the family's fears and all that kind of stuff as your own."

Patients' experiences and nursing care needs is likely to be limited if the nurses' own concerns and needs are not met. Even when nurses are confident in their professional, caring abilities, being authentically present and sharing in another human's suffering can be exhausting; nurses may chose to leave patient care altogether if the emotional costs of exposure become too great (Austin et al., 2005; Austin et al., 2003; Rourke, 2007; Wilkinson, 1987). Thus repeated exposure to dying patients can destroy the sense of safety that guides most people through life, revealing a harsh and frightening reality.

As Watson (2012) put so eloquently:

Human Caring is viewed as the moral ideal of nursing. It consists of transpersonal human-to-human attempts to protect, enhance, and preserve humanity and human dignity, integrity, and wholeness, by helping a person find meaning in illness, suffering, pain, and existence and to help another gain self-knowledge, self-control, self-caring, and self-healing wherein a sense of inner harmony is restored regardless of the external circumstances (p. 65).

Although with some exceptions, the dying patient is vulnerable and often terrified of the finality of approaching death, the grief of family members, overwhelming sadness, lack of time and resources and frequent deaths of patients can become debilitating if nurses are not equipped with the right tools to recognise and manage these emotions (Adelbratt and Strang, 2000). Because of these emotional factors, there is increased prevalence of emotional exhaustion, moral distress, anxiety, compassion fatigue and burnout among nurses that do not recognize these stressors for what they are and are therefore incapable of addressing their potential effects (Bush, 2009; Sabo, 2006, 2008; Sherman, Edwards, Simonton and Mehta, 2006). This results in increased turnover rates and may even cause nurses to permanently leave the profession (Austin et al., 2005).

The concepts of burnout and compassion fatigue are often used interchangeably to describe professional psychological and emotional stress (Keidel, 2002; Melvin, 2015). However the notion of burnout is quite distinguishable from the concept of compassion fatigue, in that burnout does not apply exclusively to caring professions and is more related to the gradual accumulation of combined stressors one experiences in the workplace (Potter et al., 2010). Abendroth and Flannery (2006) found that characteristics

of the nurse seem to play a large role in determining the risk for compassion fatigue. Their findings have been supported by later studies (Bush, 2009; Sabo, 2008) that suggest nurses working within end-of-life-care such as palliative care and hospice are at considerably higher risk for developing compassion fatigue mainly due to the nature of the work which attracts nurses that encompass high caring and empathetic attributes (Abendroth & Flannery, 2006).

As evident in Lydia's narrative, nurses often realize when they have become too emotionally invested in their patients. She stated:

I get too involved, that's the problem, and yes I think I get too close to them. I think there's a fine line, and I've had some that when they have passed it really affected me. … I think once you get too close it's hard to pull back. I think you have to stop it before you get too…but there are patients that just get to you, or you see them suffering and then it just rips you apart. …I think it's …the aftermath, it's after they're gone, after they die it's just emotionally draining for me. We see the end results of cancer, we never see the cancer patients that come in, get their treatment, go home, and actually beat it. We see the cancer patients at their sickest and the dying at the last moments.

Lydia's perception might be skewed due to the fact she only sees the end results of an otherwise long disease process which triggers our own sense of mortality. Lydia continued:

Sometimes I have to step away; there are times where I just can't…when I get two young women with breast cancers in one rotation. It hits too close to home,

but I haven't got a choice, I have to somehow go there, and it's tough sometimes. But it really does spill out into my home life, and I realize that. I mean I can be snippy and short at home because I've had a terrible day at work. How can you explain to your husband or kids that you just had a woman in her prime, die on you and her kids are the same age as mine are… my kids don't understand this and they shouldn't really... But I try not to take it home with me… it's just really hard sometimes. I mean if we are running around like crazy, maybe working short or the unit is heavy and I feel I'm not getting anything done on time, I sometimes do break. I mean that's only human.

Compassion is feeling and acting with deep empathy and sorrow for those who suffer and is a vital ingredient of having hope for and helping others (Stamm, 2002). There is a correlation with the amount of empathy the nurse feels and difficulties with emotional detachment from patients (Figley, 1995). Compassion fatigue is total exhaustion: physical, emotional, spiritual and social. The nurse becomes entangled in the downward spiral of overwhelming feelings until she/he experiences a lack of desire or ability to care and empathize with others (McHolm, 2006). With time, and persistent, non-relenting stressors, nurses may learn to depersonalise or distance themselves from sensitivity to their own emotions because they have learned and adapted enough to turn them off (Young, Derr, Cicchillo and Bressler 2011). This ambivalence to suffering or *compassion fatigue* along with moral distress is one of the major causative features in burnout (Gentry, Baranowsky, and Dunning, 2002; McHolm, 2006; Patrick and Lavery, 2007). For the nurses in this study, finding a balance between empathy, caring, and

emotional involvement was crucial to maintain the emotional health they felt needed to practice in palliative care.

Moral Distress - Questioning What Is Right

The phenomena of moral distress occurs when nurses are unable to perform according to what they believe to be ethically correct and if unresolved moral distress has been shown to cause a multitude of emotional and physical symptoms similar to that of compassion fatigue and eventually burnout (Hamric, 2014; Kleinknecht-Dolf et al., 2015). Contributing factors can be contextual, personal or professional and consistent distress is a leading cause of nurses leaving the profession altogether (Austin et al., 2005; Austin et al., 2003; Kleinknecht-Dolf et al., 2015). As noted previously, most people that enter the profession of nursing do so because of a strong desire to care for others (Watson, 2003). As Gastmans, Dierckx de Casterle and Schotsmans (1998) remind us, nurses have a unique moral obligations to the patients and families in their care as they are consistently required [to] "make choices, in particular, situations that bring about the good" (p. 46).

Angela, one of the nurse participants, became emotional when the topic turned to what she felt was distressing in her practice. She feels very strongly that people should be allowed to stay in their home for as long as they are physically capable, that keeping them in the palliative care unit is somehow a disservice to the dying patient. She stated:

Sometimes I almost argue with the palliative team in rounds, like why are they [the patients] here, they should be at home with support. …Just because they're palliative doesn't mean that they are going to die in the next twenty-four hours or

next week. I just think it's wrong. Let them go home. Even if they're home for a week and come back, that is a week that they have not had to look at these four walls. You're at home, you're sitting on a couch, and it's almost normal. It's almost like you're back to normal.

Another frequent stressor for Angela is when families insist on withholding pain or anxiety medication from their dying loved one who is clearly in distress. She discussed how she felt a sense of duty to advocate for her patients and often felt she needed to be tough. "Sometimes you have to ask the hard questions. Is this how he wanted to be? In pain, uncomfortable, breathless…" Shaking her head Angela sighed and continued:

It just isn't right, but this happens more often than people realize. You're almost catering to the family because they are the voice for the patient at that time. Right? I find that hard, because obviously someone is not doing what the patient was hoping for, and now you're not focusing on the patient, you're focusing on the family, and you have lost sight of the patient. You're just making sure that they're happy with what you're doing, and now you've lost sight of your patient that's lying in the bed.

The current medical paradigm has been and continues to be, preoccupied with curing the ailing body and to a lesser degree, focused on adequate training and education for all healthcare professionals on the multifaceted, holistic caring as death approaches. This is the backdrop of the fact that death in its finality is an inescapable and natural part of human existence (Iranmanesh, Savenstedt, and Abbaszadeh, 2008). Watson (2012) remarked:

The nursing profession has an ethical and social responsibility to both individuals and society to sustain human caring in instances where it is threatened and to be the guardian of human caring, individually and collectively, serving as the vanguard of society's human caring needs now and in the future (p. 42).

Moral and ethical distress can lead to feelings of helplessness and anger at themselves as well as the institution or healthcare system they feel is unwilling to change (Austin et al., 2005, Austin et al., 2003; Hamric, 2014; Melvin, 2015). Having to jeopardize one's personal beliefs, morals, and values on a regular basis only adds to the nurse's moral distress (Hamric, Borchers, and Epstein, 2012). However, one has to be aware that situations that cause one nurse moral distress might have different or even no effect on another; every experience is different and individual ethos, and values are culturally situated in a specific moment (Hamric et al., 2012). As is reflected in Sarah's comments on how her own values and beliefs do at times conflict with her duties as a nurse. She commented:

> It can be difficult when your own beliefs stand in way of you doing what you are asked to do... But I mean what can you really do? A few years ago the palliative team started to offer palliative sedation on the unit. It is used for patients with uncontrollable symptoms. And only when nothing else has worked. The patient is slowly sedated until they are obtunded. And they [patients] are kept in this unconscious state until the body naturally dies. I mean I know it's nothing like euthanasia… but it still feels very wrong to me, and I have a really hard time with it. I think it's just morally wrong.

Obviously upset Sarah continued:

But I do it, I mean only because I'm told to and I have to follow the physicians'
orders even if I don't agree with it. It just feels really wrong to me…but I still do
it. However, there are a few nurses on our unit that will not be involved in
palliative sedation at all, and end up switching the patient to another nurse.

Sarah sighed before she continued:

I'm worried now that Canada is discussing physician-assisted suicides... I'm not
sure I can do palliative care if that becomes legal. I mean palliation should focus
on quality of life until natural death occurs. There is nothing natural about it. My
beliefs just wouldn't allow me to even consider being involved in ending
someone's life.

Like Sarah, women nurses have been conditioned by historical tradition to follow
and adhere to the institutional hegemony, which in turn, re-enforces their relatively
disempowered status within the current healthcare system (Goldberg, 2003). No matter
how distressing it might be for palliative care nurses, physician-assisted death will soon
become a reality. Amendments to the Canadian Criminal Code section 241 is currently
being made. At present it states**:**

Everyone who (a) Counsels a person to commit suicide, or (b) Aids or abets a
person to commit suicide, whether suicide ensues or not, is guilty of an indictable
offence and liable to imprisonment for a term not exceeding fourteen years
(Criminal Code, 1985).

However, according to the Health Law Institute at Dalhousie University (n.d.); on
February 6, 2015, the Supreme Court ruled that the ban on assisted suicide violates

section 7 of the *Canadian Charter of Rights and Freedoms*. Consequently, the Court declared section 241 (b) of the *Criminal Code* invalid for a period of one year while government officials research and decide on permanent changes to the law. As a result, assisted suicide will be legal for a competent adult who clearly consents to the termination of life *and* has a critical and irreversible medical condition that causes intolerable suffering to the person. A few amendments to the *Criminal Code* have already been introduced to the Senate although none have been passed as of yet.

Contrary to Sarah's beliefs, Chiara stated an opposite stand on the practice of palliative sedation. As was evident through her opinion:

> I think in cases where nothing can be done to alleviate a person's pain or distress, it's a gift to be able to offer them the relief of sleep. Families that otherwise have to watch in horror at their loved one in such pain and distress can rest assure that they are now comfortable and without pain. I sometimes get to join the physicians when they bring up the possibility of sedation with the patient and their family. And the way they explain it just makes perfect sense. Like if you could for some reason decide how you die, most people will say *in my bed sleeping*, and that's exactly what sedation is, right? Just sleep and peace until death comes. I think it also gives the family quality time to say goodbye that allows them to come to terms with the impending death.

Palliative nurses often struggle with the conflict between their duty to follow the physician's orders and their nursing obligation to provide a comfortable and dignified death for their patients (Lazzarin, Biondi and Di Mauro, 2012). Austin and colleagues (2005), point to the fact that the historic imbalance of power between nurses and

physicians continues to flourish, regardless of the changes in the division of gender in either profession. The social construct of the healthcare hierarchy continues to support a landscape where nurse's voices are of less value and importance, leaving nurses' feeling devalued and powerless, causing moral distress.

The women nurses in the study had all struggled with the dilemma between their obligation to follow physicians' orders and their duty to provide a comfortable and dignified death. The nurses' moral distress was compounded by following orders that were in conflict with their belief that patients should be allowed to die peacefully without unnecessary pain. They felt inadequate because, as nurses, they had developed close relationships with the patient and their families. As such they were profoundly aware of the patients' desire or preferences for care. The nurses also experienced a sense of failure in that they felt they had violated their promise to the patient, in that they would make every effort to ensure they died peacefully and with dignity. According to Lassarin and colleagues (2012), this feeling of failure or powerlessness over a situation can result in a reluctance to care for that patient, insofar as the nurse feels inadequate to care ethically for her/him.

One of the greatest sources of moral distress for nurses are instances where a patient receives or undergoes what the nurse considers to be *futile* or *pointless treatments*. Supporting this view are an array of correlating studies on moral distress experienced by nurses caring for patients at end-of-life (Edmonds, Lockwood, Bezjak and Nyhof-Young, 2011; Lazzarin et al., 2012; Manara et al., 2014). Not dissimilar from the aforementioned evidence, the nurses participating in the study collectively agreed that it caused them a significant amount of distress when patients were prescribed chemotherapy at such time

the nurses felt it would only harm the patient and prolong their suffering. Brianna commented:

> I really do understand what lies behind a patients' decision to receive palliative chemotherapy. However, unfortunately, I have yet to see the good it does. I have witnessed too many people spend their last quality days or weeks in hospital, hoping for that miracle to happen. It never comes. What comes, however, is the nausea weakness and often excruciating pain. I find patients are not given the whole picture at times. They don't want to hear about the side effects that might occur, or that the treatment might actually kill them. I had a patient die with their chemo hanging, it was gruesome, and the person never should have received it. But the doctor insisted on it, nothing I said could change that. But I knew, his [patient] vitals were all off, he was starting to cool, and he was starting to acquire that specific greyish coloring. I knew for sure… Since then I have blatantly refused to administer chemotherapy to a few patients that I felt were too weak to withstand the treatment. Shaking her head, Brianna continued: But they [the doctors] just got other nurses to give it. People don't realize this. They are so focused on the word *treatment*. They feel like they are still fighting, that they are doing something. It's this misunderstanding that palliation is *doing nothing*.

Continued emotional and moral distress evoke a deep sense of sadness, ambivalence, and helplessness in nurses; lack of understanding and support from management and peers are contributing factors as the nurse slowly becomes desensitised to these emotional triggers leading to burnout (Melvin, 2015; Newsom, 2010; Sabo, 2008). All the nurses in the study shared how powerless and trivial they felt in situations

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where they were excluded by the physician from family meetings and discussions with patient and family regarding the patients' expected prognosis and treatment options. Chrystal commented, "It feels like my extensive knowledge of the patients current status is of no value, I sometimes feel ignored or dismissed. I might have had lengthy discussions with both the patient and family about what to expect." This sends mixed messages to patients and families and indicates the nurse's knowledge and opinion is not valued, which can cause moral distress (Kleinknecht-Dolf et al., 2015). Roberts (2000), maintains that the phenomena of moral distress is further complicated by nursing managers who; due to various of reasons i.e. compliance and/or administrative guidance, frequently side with hospital administrators and physicians against their own colleagues, affirming the traditional patriarchal structure within hospitals and other nursing organisations.

For healthcare institutions to be fully responsive to the needs of their nurses, the model of healthcare delivery needs to be based on human values and concern for the welfare of all persons, including the nurses practicing within the institution itself. One cannot authentically care for another, before one cares for themselves (Watson, 2012). While many institutions display posters and distribute action plans where nurses are encouraged to take care of themselves physically, including reminders for annual flu shots, quit smoking and exercise, the hegemonic hierarchy that pervasively characterizes our current healthcare system continues to reinforce oppressive power relations that persistently undervalue the voices of its nurses (Austin et al., 2005; Austin et al., 2003; Butler, 1997; Goldberg, 2003; Wilkinson, 1987). Unless nurses feel supported by their colleagues and leaders, few if any opportunities will empower them to voice their

emotional needs and seek assistance to alter their environment for change (Lobb et al., 2010; Peterson et al., 2010; Showalter, 2010).

The Ultimate Cost Of Caring

Reasons for nursing burnout are numerous and complex. From lack of institutional resources and support, emotional exhaustion related to demanding emotional practices and/or moral distress, depletion of one's psycho-social and physical resources and feeling overextended at work due to understaffing (Athlin et al., 1993; Austin et al.,2003; Austin et al., 2005; Melvin, 2015; Sinclair and Hamill, 2007; Young et al., 2011). Burnout is expressed through decreased work performance, depersonalisation or negative and detached responses to various aspects of the practice resulting in substandard care (Newsom, 2010; Sabo, 2008). The evidence has shown that nurses who experience burnout are less likely to take pride and enjoyment in their work and are less likely to participate in career advancing projects or seek opportunities for professional growth (Bush, 2009; Sabo, 2006; Young et al., 2011).

Factors that have been identified to be a major influence on palliative nurses' emotional well-being are the nurses empathy, unit workload, lack of time, patient's angst, disengaged physicians and the constant exposure to death (Gentry and Baranowsky, 1997; Sinclair and Hamill, 2007). In particular; having to bear witness to the suffering of a patient that they have developed a close relationship with, while coping with aggressive family members that have unrealistic expectations (Gentry et al., 2002). Angela remarked on the emotional toll unrealistic workload has on her, she stated:

Working short is the worst, and we do it all the time. It's horrible, I mean you might have six patients that are all really sick or even dying, and you can only run so fast. Angela hesitates before continuing: You know sometimes when I go home after working short; I feel I didn't do anything useful.

Chiara was also agitated as she reflected on the time constraints she feels is a barrier to her performance as a *good* nurse:

It is so frustrating when I am placed in a pod with five patients that all need me for absolutely everything. I mean, I end up only doing the bare minimum. That's not what nursing should be about. Giving meds on time, doing the dressing changes and sometimes my patients have to be soiled for a terribly long time because I'm stuck in another room for a long time… and then all the charting. We don't get paid overtime, so the charting has to be done before we leave. There is no time for anything else. Nursing is about so much more than just the acute tasks; we need to be able to have a conversation with our patients. Find out what they need or want. Not just prioritize them according to medication schedule or bowel movements.

Chiara sighed heavily before she continued:

I sometimes can't stop thinking about it after I go home. No matter what I do, somehow I always end up thinking about what I should have done better or what I could have done more. And I make myself a promise that next shift is going to be different and this time I will take time to do the little things, I mean it's the little things that matter… to make them [patients] feel like they matter to us, that they

are not just a task for us to complete. It is difficult sometimes, but I mean that's why so many of us end up moving to other units. We all think about it because no matter how much we want to make the time for the stuff that matters there never seems to be enough time. We really need more nurses, but it is only getting worse. And it makes me feel so useless, like I somehow am not able to do what I'm supposed to be doing. Like real nursing. Sometimes I wished I didn't have to come to work because I know what's waiting for me. Right?

A common complaint by the nurse participants was the lack of formal institutional support. Informal debriefs with colleagues to share and discuss difficult emotional experiences, were rare due to lack of time. The nurses felt that if and when they did take time for themselves and their colleagues, it was done in a hurried manner and felt as if it was time stolen from the patients. Chrystal commented:

Sometimes we just reach a boiling point. That's just human and nothing to be ashamed for. I try to tell my students that if they feel they need to cry or talk about what they are feeling and experiencing they should voice it to me, and I do take them into the quiet room and we discuss what they are feeling. [Laughter], this is what I tell them, and I know this is what we all tell our students. Then none of us really practice what we preach. I wished we had something concrete, like a required open forum every month or so. But I do feel that because we are dedicated palliative nurses somehow the consensus is that we should be able to cope with everything and they [management] don't even consider that we might benefit from some formal emotional assistance.

Muller, Pfister, Markett and Jaspers (2010) suggest that it is the number of deaths the palliative nurse experiences per week that is the main contributing factor in determining the risk of burnout. Highly empathic nurses are driven by the individuals' needs for their care and expertise, something that can lead them to become overly involved with their patients and their families blurring the personal/professional boundaries (Abendroth and Flannery, 2006; Bush, 2009; Sabo 2008). Their pain and suffering becomes the nurses' failure, and feelings of incompetence are allowed to foster.

Chrystal admitted to have experienced burnout earlier in her career when all the suffering she was witness to on a daily basis started to affect her ability to provide quality care. She reflected on this difficult time in her practice as she stated:

All of a sudden I had nothing left to give, I felt empty. I was just so incredibly fed up *toe-tagging* people every day. And some of them were people I knew from my own community, I lost two girlfriends during this time, and I think the loss just added to my sadness and hopelessness it just became overwhelming… no joy anymore. I became pessimistic and angry at everyone. It felt like everyone that I knew got sick ended up dying. I was having such a hard time coping with the grieving families that I found myself avoiding them. I couldn't have hope for myself or my patients. At least I knew I had to leave; I needed to take care of myself for a bit and do something totally different, like far away from the sadness, crying, hopelessness and death that seemed to fill my days in the palliative care unit. And I did… for a long time. I just needed not to see the suffering anymore. I was able to recharge myself and kind of rediscover why I love nursing. Chrystal laughed and shook her head, -and then, when I was ready, I came back.

First, Love Thyself

When nurses continue to work in distressing environments, their feelings of professional failure, guilt, and inadequacy, it can have adverse consequences on their psyche and sense of self (Edmonds et al., 2011). This emotional turmoil can spill out into their personal life and lead to various adverse psychological and physical symptoms (Sabo, 2006). When nurses care for patients over extended time, they are reminded of their own mortality and the fragility of life. Despite the recognition by palliative nurses that relations with patients and families are grounded in compassion, respect, integrity and authenticity, with the goal of easing suffering toward a dignified death (Halldorsdottir, 2008; Watson, 2003, 2008, 2012), the palliative calling as a nurse is both exhausting yet profound: It is a revolving cycle of beginnings and endings. When a patient dies, nurses must find closure, say goodbye, and clear their heart space in order to authentically welcome a new person into that space—a caring space (Duggleby and Wright, 2007; Duggleby, Cooper, and Penz, 2009; Penz and Duggleby, 2011).

Lack of professional collaboration along with lack of educational emphasis on palliative care, are also contributing causes of distress for practicing nurses (Lazzarin et al., 2012). Inadequate communication skills along with lack of knowledge and expertise in grief and grief therapy will thwart nurses from making themselves authentically available to comfort patients and family members (Duggleby et al., 2009; Iranmanesh et al., 2008). Self-reflection, meditation, mindfulness, collegial and institutional support along with unit de-briefs, and education on grief and grief therapies are all means for nurses to stay emotionally well and prevent harm to their own psyche (Becker and

Lauterbach, 2005; Edmonds et al., 2011; Heard, Hartman and Bushardt, 2013; Pereira, Fonseca and Carvalho, 2011, 2012; Watson, 2012).

A reflexive approach to self-care and everyday nursing practice requires a conscious and critical self-examination in an attempt to politicize one's practice. To locate *self* within one's socio-cultural and politically acquired biases, prejudices and assumptions about *other* that often influences and directs nursing care. Resulting in increased awareness of how these biases can inhibit the fundamental values of nursing that include social justice and health care equity (Goldberg, forthcoming 2015).

Despite the emphasis in nursing to care for others, care of the self is fundamental if nurses are to remain healthy in our current health-care environments. Caring for *self* includes holistic self-assessment, personal development, and being aware of mind-body-spirit as one as an instrument of and for healing (Watson, 2008). Living intentionally, and understanding how to use relaxation techniques to recognise triggers can assist nurses to live each day fully, and foster an ability to adhere to their professional and personal values in their environment: personally and professionally (Hunnibell, Reed, Quinn-Griffin and Fitzpatrick, 2008; Potter et al., 2010). Journaling and other conscious acts that convey a will and intention to care can refuel ones heart and soul, restoring a passion for caring for others (Heard, Hartman, and Bushardt, 2013).

It was evident throughout the nurse's narratives that there is a genuine desire and need to be understood and listened to by colleagues. Lydia and Angela for example both carpool with different colleagues to and from work; they find comfort in sharing their emotions, sadness or joys, during the long commute. Providing the space to voice out

loud the shared experience creates a level of non-judgemental and mutual understanding. As Angela noted:

> We kind of de-stress or dump everything on our way home. I mean we talk it out. I find that makes me feel much better. But I don't really do anything special. I find my nursing partners are enough.

The same caring relationship these women nurses strive to establish with their patients could be taken away from the bedside and incorporated into structured collegial debriefs. Similarly to Cameron's (2004), the *how are you* question in the context of palliative care, can easily be asked by a trusted colleague. This can give way to a safe and caring relational space where nurses can engage each other by sharing their stories and express their feelings without being judged (Goldberg, 2005, 2008; Ryan et al., 2010).

Practicing self-care results in the empowerment of nurses to take a more assertive role and to have their voices heard regarding their patients and practice environment (Mariano, 2007). Support meetings, or debrief sessions enabling nurses to openly discuss emotionally challenging cases has been shown to be beneficial to nurses emotional wellbeing (Athlin et al., 1993; Seed and Walton, 2012). Further, peer support allows nurses to share and discuss what they consider to be important in maintaining their professional and personal competencies (Sandgren et al., 2006). As Watson (2012) reminds us:

> What is essential in human existence is that the human has transcended nature – yet remains a part of it. The human can go forward, through the use of the mind,

to higher levels of consciousness by finding meaning and harmony in existence (p. 57).

In line with Watson's words, purposeful self-reflexivity and awareness of how ones' self, fits within the world are key components in the nurse's search for meaning and purpose when caring for emotionally challenging patients (Athlin et al., 1993; Bush, 2009; Hunnibell, Reed, Quinn-Griffin and Fitzpatrick, 2008; Pereira et al., 2012; Sabo, 2008; Seed and Walton, 2012; Young et al., 2011). Learning to successfully cope involves acquiring acceptance of the world as it is. Coward and Reed (1996) examined the notion of healing in a context that does not involve *curing* the physical body, but the soul. The authors explain the notion of self-transcendence as a concept of human potential to exist outside of one's physical boundary within their own spirituality. This the authors conclude, allows for a pandimensional awareness of self that can facilitate healing through coping and acceptance of one's circumstances or terminal disease (Coward and Reed, 1996). As Brianna's narrative illuminated:

> How can I practise loving others, if I don't have love for myself? I wouldn't be able to function the way I do if I didn't meditate, and transcend my mind to places of love and peace. In that state, I explore my feelings from within and it allows me to let go of any and all frustrations, anger and sadness I might have stored in my soul. I find my center, my heart, and I feel the love for the universe being replenished.

> Brianna looked at me and laughed before continuing:

It really isn't as weird as one might think… It is healing for me. I become one

with the universe, in a sense; [we] are all interconnected on this higher level of

being. It is my ritual of letting go, I send a message into the universe, telling my

patients that it's all right to let go and become one with the universe. If a

particular patient has passed on, I send love into the universe as a farewell to

them, and I thank them for allowing be to be a part of their journey.

The profoundly insightful narrative by Brianna reflects the notion of self-

transcendence. Self-transcendence is a learned process that can facilitate emotional

health. As such, it can become a valuable tool to manage work-related stressors and

should be a technique to foster in palliative care nurses and their patients and families

(Reed, 1991; Enyert and Burman, 1999). Self-Transcendence is about coming to terms

with who you were, who you are and where you are going; it demands a look inward and

the work to reflect on the inner self in search of personal strength to use in the present to

assist in guiding future practice (Enyert and Burman, 1999). It involves consciously

connecting with the higher level of the environment and persons within it. This allows

oneself to reflect on one's own biases and boundaries, thus remaining open enough to

hear and absorb information from others (Hunnibell, Reed, Quinn-Griffin and Fitzpatrick,

2008; Reed, 1991).

Despite the ability for some nurses, including those in the study to benefit from

self-care practices (self-transcendence), institutional support for nurses in emotional

distress is often not available and nurses have to seek assistance from outside sources

(Wellspring, 2015). Innovative networks of community support centres in Alberta and

Ontario have developed an interventional program for nurses and other healthcare

professionals working with terminally ill and dying patients (Wellspring, 2015). *Care for*

the Professional Caregiver Program (CPCP) was founded to address the complex

emotional issues that front-line nurses and other healthcare professionals face on a daily

basis. Their aim is to assist individuals to develop coping strategies to manage the loss,

grief, and other stressors that many front line nurses experience in their work life and

adversely affects both their personal and professional well-being. Education is focused on

grief and loss, emotional distress and burnout as experienced by front-line health

professionals (2015). Practical hands-on supporting measures include self-reflection,

guided imagery, debriefing dialogue, and other self-care practices that focuses on coping

skills that have been shown to empower the front-line nurse and mitigates the effects of

burnout (Gentry and Baranowsky, 1998; Gentry et al., 2002; Wellspring, 2015).

Conclusion

The highly demanding and complex nature of palliative care results in numerous

occupational stressors for frontline palliative nurses (Duggleby et al., 2009; Arnaert,

Seller, and Wainwright, 2009; Penz and Duggleby, 2011). The evidence suggests that the

first step in preventing nurses from developing distress, compassion fatigue, and burnout,

is the recognition that there is a potential problem (Abendroth and Flannery, 2006; Bush,

2009; Melvin, 2015; Sabo 2008). Further, constructive regular support from

organizations themselves are needed to identify and assist those nurses in need (Newsom,

2010; Sherman et al., 2006; Yoder, 2012). Only by understanding the nature of the

problem can we in the caring professions start taking the preventative measures needed to

shield nurses from the price of caring (Figley, 1995). In the current healthcare model,

nurses are encouraged to prioritize their time, yet little to no time is allotted to the nurse's own emotional wellbeing (Sandgren et al., 2006).

Each nurse must discover and nurture her/his inner strength in order to balance the toll nursing can claim on the spirit. The path to self-discovery is not travelled in haste nor without careful planning (Hentz and Lauterbach, 2005). Healing is found in many forms, but reflexive practice is essential (Bolton, 2010). Journaling, meditation, positive self-talk, time in the company of friends and family, spiritual fulfillment, or tea with a colleague to de-brief are but a few examples (Edmonds et al., 2011; Watson, 2008). And, for the palliative nurse, this becomes more profound, given they dwell so closely with life and death with the patients and families in their care. Brianna described finding comfort and solace discussing her feelings with a trusted colleague that understands the stressors and heartache of working in palliative care. In what follows, I offer the beautiful and powerful words Brianna wrote her trusted colleague in the following poem:

I am whole
I am whole because I was listened to
I am whole because a hand reached out to me
I am whole because a heart opened up to me
In spite of all the sorrow surrounding me

I am whole because I was given help to become whole
I am whole because you helped me see how to cope
Helped me see how to hope
Gave me strength when I thought all was lost
Which I am sure at times was at a great cost

You never showed that cost to me

You never made it just your *job*

All I saw was dedication, compassion and love

It is because of this

I am whole

Chapter VII   Conclusion

"Nursing's social, moral, professional, and scientific contributions to humankind and

society lie in its commitment to sustain and advance human caring values, knowledge,

practices, and ideals in theory, practice, education, and research" (Watson, 2012, p. 44).

The Purpose Of This Research

The primary purpose of this research was to acquire a deeper understanding of

and find meaning in the experiential human condition of hope, as understood from the

gendered experiences of nurses in palliative care. Using a feminist phenomenological

approach to interpret the participants' narratives, the intimate yet complex and diverse

journey of palliative nurses were recorded. How we as a society care for the dying is an

indicator of how society cares for all sick and vulnerable people (Walling et al., 2010).

Dame Cicely Saunders (1988) once remarked, "How people die remains in the memory

of those who live on" (p. 625). As Angela, one of the nurse participants explained when

talking about family members of those you are caring for:

> They remember you, and they remember your name and everything you ever
>
> did… they will search you out…because they trust you, and they know that you
>
> are looking after mom or dad.

Caring for those approaching death can be one of the most important and

rewarding areas of nursing practice, although it is both challenging and emotionally

demanding, as is evident by the participants' stories. However, what permeated

throughout the nurses' narratives was also the understanding that if the necessary

knowledge, skills and attitudes were fully cultivated, palliative care could also be immensely satisfying.

Summary Of The Findings: The Four Themes

Four main themes emerged from the participants' narratives by ways of analysis and researcher interpretation: the embodiment of human caring: attending the physical body during palliative admission; coming to know in the nurse's engagement of hope in palliation; stereotypes and generalizations of gender and caring: moving beyond our historical legacy; and from empathy to burnout and back: cultivating self-care practices to heal the palliative nurse.

The first theme explored how a caring, trusting relationship that sustains the duration of palliation begins. It is in that critical moment, when a nurse first gazes upon her/his patient and embodies the potential to create an introductory relationship that is unlike all other relationships in care (Goldberg, 2005, 2008). This theme moves beyond the introductory moment to further explore nurses' experiences in attending to the physicality of patients' acute bodily needs upon admission to the palliative care unit. This includes the fundamental role nurses play in supporting patients' and families during palliation of their loved ones, often against the institutional health care landscape pervasive with gendered, hierarchical and power dynamics (Goldberg, 2005). The nurse participants collectively felt that initial encounters with patients were often acuity focused; Primacy given to the *skill* of relieving the acute suffering of the physical body being admitted into the palliative space, before psychosocial care could be given to the patient or her/his family.

Ensuring that patients feel safe is vital in establishing trust during initial admission to the palliative care unit, as patients are often admitted in a physical crisis accompanied by enormous sadness and grief. To be in the moment *with* the patient, as often words and conversation halt in favour of silent togetherness and touch takes the place of conversation. Holding hands or gentle stroking of the forehead carries all the communication needed. In essence, this theme illuminated an understanding of the complexities admission to a palliative care unit entails, how the transpersonal, nurse-patient relationship is initiated and sustained through embodied trust and the nurses authentic caring and compassion.

For the dying patient, the nature of their hope changes throughout the course of their illness, as one kind of hope becomes unattainable and, therefore, may be replaced by another. The hope for full recovery becomes replaced with the hope for a quality time with family and peaceful death (Kylmä, Duggleby, Cooper and Molander, 2009).The process of trust building and hope is discussed in the second theme entitled, *"Coming to Know in the Nurse's Engagement of Hope in Palliation."* By way of analyzing the nurse's narratives and data derived from observational findings carried out on the palliative care unit, the importance of *hope* within the palliative care space is illuminated. As Sarah commented: "If people don't have anything to hope for… what is there to live for?" Yet as apparent from the nurses' stories, one cannot begin to engage the patient through hope without first *coming to know* the *person* removed from his disease.

This theme explored the various methods the nurses used in their practice to support their patients in finding meaning and hope in the (ab)normalcy of their lived reality. The powerful words of Anne Frank (1952) encompass the true meaning of hope.

She wrote: "I don't think about all the misery, but about the beauty that still remains" (p. 157). This theme illuminated, for example, how the genuine act of kindness, through the simple act of serving tea and cake with a warm smile, can bestow hope and happiness to those that accept it, giving purpose and strength to courageously face the day as it comes.The nurse-participants embodied the nurse-patient relationship by way of mutual engagement, trust, and respect by exploring the physical, psychosocial, and existential needs of their patients (Carman et al., 2013; Goldberg, 2005, 2008; Goldberg et al., 2009; Watson, 2012). Luker and colleagues (2000) suggested that mutual engagement between a nurse and a palliative patient is in "*the coming to know*" and thus a crucial precursor for quality care delivery. A truly relational, authentic engagement between a dying patient and nurse has the power to ease suffering and bring hope and purpose into the life of the patient (Duggleby and Wright, 2007, 2009; Olsman, Leget, and Willems, 2015).

The third theme titled: "*Stereotypes and Generalizations of Gender and Caring: Moving Beyond our Historical Legacy*" examines the nurse participants' experiences and understanding as they relate to cultural and gender stereotypes still apparent within our modern day practices as nurses. Historically, women have been demoralized as the lesser sex and nursing as a profession has been deemed *women's* work (Henly and Moss, 2007). The women nurses in the context of the study have been historically socialized to accept socio-cultural perceptions of *self* largely constructed within a hegemonic healthcare system. Unfortunately, as evident by the participants' narratives, our current healthcare system remains pervasive with gendered discrimination and oppressive power relations. Despite these challenges, men nurses within the profession offer a renewed understanding of gender as it relates to caring that moves nursing beyond its feminized origins as solely

women's work (Evans, 1997, 2002; Watson 2003, 2008, 2012). This disrupts the current norms that continue to perpetuate the stereotype that nursing and caring are solely *female* attributes. In so doing, this shift broadens the current mandate of nursing and the role of caring within clinical practice (Cudé and Winfrey, 2007; Goldberg, 2003).

This theme further highlights that any behaviour that perpetuates discriminatory stereotypes and norms can work to harm the future of nursing practice. However, as evident in the participants' stories, patients in their care come from various cultural backgrounds with vast variations in beliefs, values, and norms. Many nurses trust that by treating every patient with the same caring attribute and respect they will elude any misunderstanding related to their cultural differences (Galanti, 2000). Nevertheless, as illustrated from the narratives, challenges can easily arise as nurses unwittingly stereotype and display ethnocentric views of patients from patriarchal cultures, despite good intentions, as they navigate the fine line between cultural sensitivity and ethical boundaries

The fourth and final theme explores the emotional toll of nursing. In the theme *"From Empathy to Burnout and Back: Cultivating Self-Care Practices to Heal the Palliative Nurse"* the nurse participants' honestly discuss how abundance of love, empathy and the genuine desire to care for others combined with consistent exposure to patient suffering can directly cause varying degrees of physical and psychological symptoms (Athlin, Furåker, Jansson and Norberg, 1993). Embedded in the heart of palliative care lies the mutual, trusting and embodied relationship nurses establish with patients and their families (Halldorsdottir, 2008; Santos Salas and Cameron, 2010).

However, what permeates the nurse participant narratives, is how the complexities of this level of care requires intimacy to such degree it has the potential to cause the nurses emotional distress, compassion fatigue and burnout (Athlin et al., 1993; Bush, 2009; Sabo, 2006, 2008; Sinclair and Hamill, 2007). Such distress can have lasting effects on nurses' personal and professional lives, resulting in physical exhaustion, emotional detachment from patients, and increased work dissatisfaction that may cause nurses to leave the profession altogether. Additionally, this theme highlights the need for increased organisational attentiveness towards bedside nurses and a realization that the immense value the overall, holistic, wellbeing of each nurse is to the intricate care of their patients (Battistelli, Galletta, Vandenberghe and Odoardi, 2015).

In light of this *potential cost of caring*, this theme emphasizes the importance of incorporating self-care into everyday practices and explores different methods of coping with work-related stressors. The nurses discussed the diverse and complex ways in which self-care practices had allowed them to obtain closure and heal their hearts when the emotional burden of caring became too heavy to bear. Bringing them to the conclusion that *love* in its purest form, resides at the center of their commitment to caring practice (Watson, 2007, 2008, 2012).

Implications For Education, Practice And Research

The knowledge generated from the study informs our understanding of the complexities of caring work as it is experienced by women nurses in the context of palliative care. Findings will serve as a foundation for my own workshop development that focuses on incorporating self-care into everyday practice, and various methods of coping with work-related stressors. While self-care amongst nurses is essential, as

indicated in the findings, it must be considered in conjunction with peer and collegial support to further foster space for nurses to heal. This will more broadly provide spaces and places for nurses to gain support and sustain their work in order to provide the kind of care necessary for quality palliative care. A deeper and more profound understanding of how dying individuals view and experience hope can be utilized by nurses in implementing strategies that both promote and maintain hope with patients in their care. Therefore, it has the potential to inform future policy and practice changes that support a shift in focus to further advance palliative practices, both in relation to provision of care and formal and informal support for nurses' self-care practices.

These findings have the potential to inform future education and training of healthcare providers, especially nurses in holistic palliative care that focus on the importance of hope and caring that is humanized and not feminized. While the research findings are based on a very small sample, when understood in the broader body of literature in relation to men in nursing, the implications can offer significant insights into the gendered experiences of nurses in all areas of practice, particularly as it relates to aspects of caring practices and why nursing must move beyond feminized versions of caring to advance the profession for all nursing professionals.

Translating knowledge gained from this study into palliative care practice is imperative. Study findings have much to offer, particularly when understood in the context of the broader body of evidence on gendered experiences, palliation, nursing, and the role of hope in death and dying. Findings will first be presented to the palliative care team at Southlake Regional Health Centre, including nurses, physicians, social workers and spiritual care, followed by open forum discussions. Secondly, small workshops and

in-services detailing the findings will be held and be open to all nurses currently working on the palliative care unit as well as those interested in caring for palliative patients. Nurse participants from the study will all receive copies of their transcripts and detailed study results, which if they so choose, they will be free to share and discuss with their colleagues. Collectively, the nurses in this study displayed a passionate commitment to quality patient care and found that participating in the interviews encouraged them to reflect critically on their own practice. Findings from this study will be shared via conference presentations, seminars and publications with the potential to reach other healthcare providers, researchers, and educators.

The study serves as a starting point for further research into the gendered experiences of nurses in the context of care provision for culturally diverse populations in palliative care. My hope is that nurses reading this work will be able to locate aspects of themselves and their practice within the shared narratives of the participants, allowing for inward reflection and increased awareness of the complexities of palliative care that potentially have commonalities shared by all areas of practice. Findings will potentially inform the education of healthcare providers working in palliative care, including practicing nurses, physicians, as well as those training in undergraduate, graduate, post-graduate and continuing education, particularly when understood in the broader context of evidence related to palliative care. For example, if students are introduced early in their undergraduate programs to this unique area of practice, where emphasis is placed on developing intimate and trusting relationships with patients and families (Duggleby and Wright, 2007; Halldorsdottir, 2008; Santos Salas and Cameron, 2010), there is great potential to attract more nursing students to this area of nursing (Zimmerman, 2007).

Self-Reflection And Concluding Comments

I was privileged in being allowed access to and peek into the world as it was lived by the six women nurses that participated in the study. After listening to and reflecting on the nurse participants' narratives, I have a renewed respect and profound understanding on the complex challenges that palliative care nursing entails. How intimate and relational their approach to caring is, all while holding on to the emotional roller-coaster with both hands. Facing everyday sorrows alongside small joyous victories. Finding courage to return each day with the love for their patients and the unconditional support from trusted colleagues. Having been a palliative care nurse for many years, it is a remarkable experience to re-discover the profession again, with help from the brave nurses that participated in this study.

There have been many challenging aspects to this journey. Writing a feminist phenomenological piece of work was a new experience for me. It demanded a view of the world and my work through a totally new lens. A lens I knew I was already familiar with as a woman and a feminist, yet, I quickly came to find I needed frequent refocusing. My familiarity with the subject forced me to take a step back and reflect on my own practice, being careful and cautious, reminding myself constantly not to make assumptions based on own experiences as a clinician with many years as a palliative care nurse.

During my observational shifts, I was privy to numerous acts and conversations that, although pertinent to my thesis, I struggled with including due to consent and confidentiality issues. During these observations, I was witness to raw grief as death occurred, and the joy of accomplished goals. The love that permeated the unit was

tangible. I felt the strong comradery between every member of the care team and how fiercely protective they were for each other and their patients.

As a living entity, the profession of nursing continues to evolve and transform itself according to society's needs. Therefore, it is fitting to end with the words of a former president of the Canadian Nurses Association, Dr. Deborah Tamlyn (2007),

> We in nursing are constantly pushed by the prevailing winds of change. Our challenge is to respond like sailboats surrounded by wind, even dependent on it, but using that wind to shift and choose the direction forward. Nurses will navigate the troubled waters of health care and arrive on a safe shore by embracing leadership, innovation and change, and continuous learning (p. 53).

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Appendix A: Recruitment Flyer

DALHOUSIE
UNIVERSITY
Inspiring Minds

Palliative Care Nurses: A Research Study

What do nurses in palliative care consider supportive and/or challenging in maintaining hope while providing care?

To what extent do nurses consider gender influencing their provision of care (or not), and in particular their understanding of the concept of hope?

Explore these and other questions in a research study titled "The Gendered Experiences of Nurses in Understanding Hope in Palliative Care"

If you: Are a Palliative Care nurse
With at least three years' experience in palliative care.
Willing to discuss the topic of interest at length.

I want to hear your story!

I am seeking women to participate in a one-on-one interview approximately 60-90 minutes long. If you may be interested, please contact me for more information:

Gudlaug Einarsdottir, 416-857-1332, gd955462@dal.ca

Disclaimer: Volunteering to take part in this study does not confirm your participation as all prospective participants will be required to submit a demographic survey to determine eligibility to participate and selected with the objective of variability.

Appendix B: Telephone and E-mail Script

<u>Telephone and E-mail Script</u>

Hello. May I please speak with [insert potential participant's name here]?
I am a Master of Nursing student at Dalhousie University and I am doing a research study
titled "The Gendered Experiences of Nurses in Understanding Hope in Palliative Care"
I received your email/phone call expressing interest in participating. Is this a good time
for you to discuss this? (If yes, continue. If no, arrange a time to call back).

I would like to provide you with more information about the research. I am trying to
understand to what extent nurses consider gender influencing their provision of care (or
not), and in particular their understanding of the concept of hope. Right now I am
recruiting interview participants. The interview would be digitally recorded, be
approximately one hour long and I would ask questions about your experiences as a
palliative care nurse and how gender has influenced your practices and understanding of
hope while providing care to palliative patients.

To be part of the study, you must have at least three years' experience in palliative care
nursing and be willing to discuss the topic of interest at length.

The interview would take place at a time and place that is convenient for you and I will
conduct the interview myself.
Do you have any questions? [Respond to questions]
Do you think you might be interested in participating? [If yes, continue. If no, end call
and thank her for her time]

I am looking for participants who represent a wide range of backgrounds. In order to
ensure I have this wide range, I need to collect more information about you before I can
set up an interview. The collective demographic data will be used to select participants
with maximum variation in age, educational background and nursing experience.

Are you willing to answer a few demographic questions? If yes, continue to Appendix C-
Demographic Questionnaire. If no, end call and thank her for her time.

Appendix C: Demographic Questionnaire

Age_____

Level of nursing

education_____

Additional secondary/post-secondary education: Yes ☐   No ☐

If yes: Degree/Certification earned_____

Length of current employment_____

Have you only practiced in palliative care?   Yes ☐   No ☐

If no: Within what field have you previously practiced nursing _____

_____

_____

Have you practiced nursing outside of Canada?   Yes ☐   No ☐

If yes: Where? _____

Total years practicing as a Nurse_____

Appendix D: Interview Consent Form

Title: Gendered Experiences of Nurses in Understanding Hope in Palliative Care

Introduction:
You are invited to participate in an interview. This interview is one part of a research study examining to what extent nurses consider gender influencing their provision of care (or not), and in particular their understanding of the concept of hope within palliative care.

Gudlaug Einarsdottir, Master of Nursing student at Dalhousie University, is leading this study.

Your participation in this study is voluntary and you may withdraw from the study at any time. The study is described below. This description tells you about the risks, inconvenience, or discomfort which you might experience. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this study with the researcher.

Participation in the interview will take approximately 60-90 minutes of your time.

Contact Information:

Primary Investigator	**Research Supervisor**	**Southlake Regional Hospital**
Gudlaug Einarsdottir	Lisa Goldberg, RN PhD	Jane Casey, RN, MScN
2 Keremeos Crescent	School of Nursing	Director of Medicine
Richmond Hill, Ontario	Dalhousie University	596 Davis Drive
gd955462@dal.ca	5869 University Avenue	Newmarket, Ontario
(416) 857-1332	lisa.goldberg@dal.ca	(905) 895-4521
	(902) 494-2988	

Purpose of the Study
The purpose of this study is to acquire a deeper understanding and meaning in the experiential human condition of hope, as understood from the gendered experiences of nurses in palliative care. To discover the potential ways in which nurses gendered experiences shape their perspective of hope and how these experiences can in turn affect the care they provide the dying patient.

Study Design
A total of 5-7 nurses from the Palliative Care Unit at Southlake Regional Health Centre in Newmarket, Ontario will be recruited to participate in one-on-one interviews.

Who can Participate in the Study
Women nurses with minimum of three years' experience in palliative care nursing, who are legally qualified to practice nursing in the province of Ontario and capable of communicating their experiences in comprehensive English. Volunteering to take part in this study does not confirm your participation as all prospective participants will be required to submit a demographic survey to determine eligibility to participate and selected with the objective of variability.

Who will be Conducting the Research
Gudlaug Einarsdottir, Master of Nursing student at Dalhousie University will be conducting the research. If you agree to participate, you will be interviewed by Gudlaug Einarsdottir, Primary Investigator. Gudlaug Einarsdottir who is also a part time employee of the hospital acknowledges that she might be known to the proposed study participants. At such time the proposed study is introduced she intends to disclose verbally any potential or perceived conflict of interest to potential participants in order to minimize the potential for conflict of interest. At the beginning of any and all discussions with potential participants she intends to express explicitly that participation is completely voluntary and stress that potential participants should not feel undue pressure or feel compelled to participate. Gudlaug's role is multifaceted and she works within multiple areas of the hospital. She works closely with the cancer centre pharmacy as well as individual Oncologists in developing and writing standardized order sets for in-patient chemotherapy. She also arranges for province approved training in chemotherapy administration for qualified RN's as well as assist units outside of medicine (cardiology, ICU) in administering cytotoxic drugs.

What you will be asked to do
You are being asked to take part in an interview. In the interview you will be asked questions about your palliative care experiences. This interview will be recorded and later typed up. The interview will take place at a time and location that is convenient for you. Below, you will be asked if anonymous quotes from this interview can be used in publications from the research study.

Confidentiality and Anonymity
Anonymity: Your name will not be used in anything that is written or presented about this research. The researcher will not tell anyone your name. An identification number

was assigned to you when you first contacted the researcher about possible interest in the study. The one file that links your ID number and your name is kept in a locked filing cabinet in the researcher home office.

Confidentiality: The digital recording of your interview will be stored on the researchers' private computer. It will be in a hidden file in the computer and will be password protected. The typed up version of your interview will also be stored on the computer, and password protected. Your name will not be in it, and anything that identifies you during the interview will be changed or taken out when your interview is typed up. Although the researcher agrees to keep everything you say private, we cannot ensure that confidentiality and anonymity will be maintained. Due to the small number of participants, there is a possibility that you will be recognized by the direct quotes used in this study.

Your Rights: You can choose not to answer any question that is asked. You can take a break at any time. You can stop the interview at any time. At that time you can tell the interviewer if you want the recording of your interview erased, or if we can still use what you have said so far. You can receive a copy of the final report. You can ask researcher any questions you want to about the study.

Possible Risks and Discomforts
It may be uncomfortable, and even distressing talking about your experiences as a palliative care nurse. Keep in mind that you do not have to talk about anything you do not want to.

Possible Benefits
The study will not help you directly, but it could provide a better understanding on how gender influences the practices of palliative care nurses and their understanding of hope which may offer us new insights for optimizing care. This may contribute to developing best practice guidelines, educational curricula, and continuing education for palliative care nurses.

Compensation/Reimbursement
You will not receive compensation for taking part in this study.

> **If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact Catherine Connors, Director of Dalhousie University's Office of Human Research Ethics Administration, for assistance at (902) 494-1462.**

I have read the consent form about this study. All my questions have been answered at this time and I agree to be part of this study. I know that I am free to stop being part of this study at any time. I have been given a copy of this signed consent form.

_____ I consent to having this interview recorded

_____   _____

Participant's Signature   Date

_____   _____

Researcher's Signature   Date

_____ I would like to receive a summary of the final results of this study.

Contact information: _____

_____

_____

I consent to the research team including anonymous quotations from my interview in publications and presentations from this study.

_____   _____

Participant's Signature   Date

Appendix E: Interview Guide

These questions are intended to be an interview guide rather than a script. The interviewer will follow participants' lead, exploring these topics but not always in this order. Ideally the participant's narrative will unfold with fewer questions rather than more.

1) Can you talk a little about where you work in palliative care and what brought you to this area of nursing? (Probes: was this always of interest? When did you know this area of nursing was the best fit for you? What is the unit like; the space; the location; the people)

2) Tell me about a specific experience in your practice where you became particularly engaged and involved with a patient or family member? (Probes: What was the context of the co-creation of that relationship? What were your hopes for that patient and her/his family and how did you nurture this in your engagement through practice?)

3) Tell me about a particular experience in your practice where you had difficulties creating trusting and caring relationship with a patient and or family member? (Probes: What strategies did you utilize to initiate a relationship? How was your initial engagement with that patient and her/his family? How did your care reflect the hope you had for that patient/family?)

4) To what extent does hope factor into your own role as a palliative care nurse (or not factor into your role as a palliative care nurse?) (Probes: if participant doesn't see hope as relevant to care; consider other concepts that they may use in lieu of hope).

5) What do you as a palliative care nurse, consider supportive in maintaining hope while providing care? (Probes: activities; interactions; environment; other providers, etc).

6) What do you as a palliative care nurse consider challenging in maintaining hope when providing care? (Probes: activities; interactions; environment; other providers; etc)

7) Can you provide a concrete example of when you were able to incorporate an aspect of hope in the provision of your care with patients and families?

8) Can you provide a similar example of when you were unable to incorporate hope in your care with patients and families?

9) Do you think hope in palliative care is expressed differently by female care providers? (Why or why not and provide examples)

10) To what extent (if any) does gender influence your provision of care? (Probes: women patients; men patients; transgender patients; etc).

11) Discuss the ways in which your own gendered experience influences (or not) your view of yourself as a care provider? (Probes: To what extent does being a woman influence your care provision; consider anything you might consider supportive or challenging in relation to your gender and gendered positioning within the institution).

12) In what ways might this translate back to the way you approach care provision with patients/families/colleagues/other providers/physicians?

Appendix F: Transcriptionist Confidentiality Form

Transcriptionist Confidentiality Agreement

Project Title: Gendered Experiences of Nurses in Understanding Hope in Palliative Care

Principal Investigator: Gudlaug Einarsdottir

I am working as a transcriptionist for the above-named study. I agree as part of this work to provide complete confidentiality concerning what is said in the interviews and any other information that may contain potentially identifying information about the research participants. I will not talk to anyone about the personal identities of the individuals who participate in the interviews. In addition, I will maintain all study data in a secure, locked cabinet or on a secure, password-protected desktop computer.

Name of Individual:

_____

Signature of Individual:

_____

Date: _____

Witness Name:

_____

Witness Signature:

_____

Date: _____