

**The Lived Experience of Nurses Providing End-of-Life Care to Patients on an Acute
Medical Unit**

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Abstract

Meeting the health care needs of patients is becoming more complex as individuals are living longer and often with multiple chronic health conditions. In Canada, the majority of patients will die in hospitals (Statistics Canada, 2009), many on medical units. Studies of hospital care have shown that end-of-life care (EOLC) could be improved. Qualitative nursing research studies on EOLC in hospital medical units have been few. More needs to be known about nurses' experience of providing EOLC within the medical unit environment.

The purpose of this study was to seek to understand the lived experience of nurses on a medical unit providing EOLC to patients. Interpretive phenomenology using van Manen's (1990) approach guided the methodology and analysis of the findings. Face to face interviews with 10 nurses on two hospital medical units were audio-recorded, transcribed and analyzed.

The underlying essence of these nurses' experience was that of "battling a tangled web". Battling a tangled web represented the nurses' struggles in attempting to provide EOLC in an environment which was not always conducive to it. Seven themes were generated from the analysis of the data: caring in complexity, caught in a tangled web, bearing witness to suffering, weaving a way to get there: struggling through the process, creating comfort for the patient, working through the dying process with the family, and finding a way through the web. These findings add to our growing knowledge of nurses' roles and actions as part of EOLC. It also highlights nurses' perceived facilitators and barriers to EOLC within the medical environment.

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Para a minha familia. Meus pais, João e Ligia; meus irmas, Ines, Elvina, e Alina; e meu irmão John; obrigado por me apoiar em tudo o que importa. Eu te amo.

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Figure 1: Working Through the Tangled Web: Facilitators to End-of-Life Care

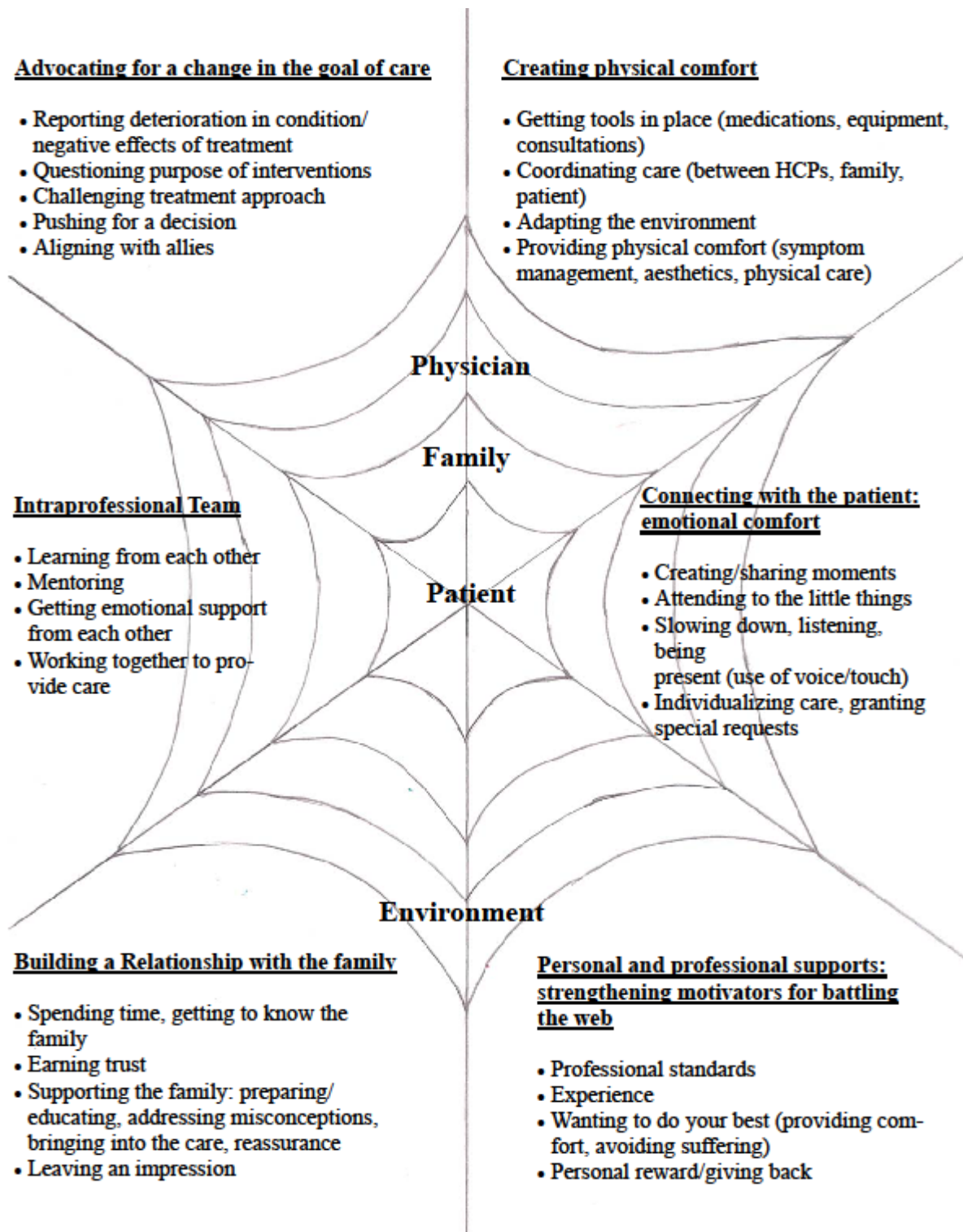
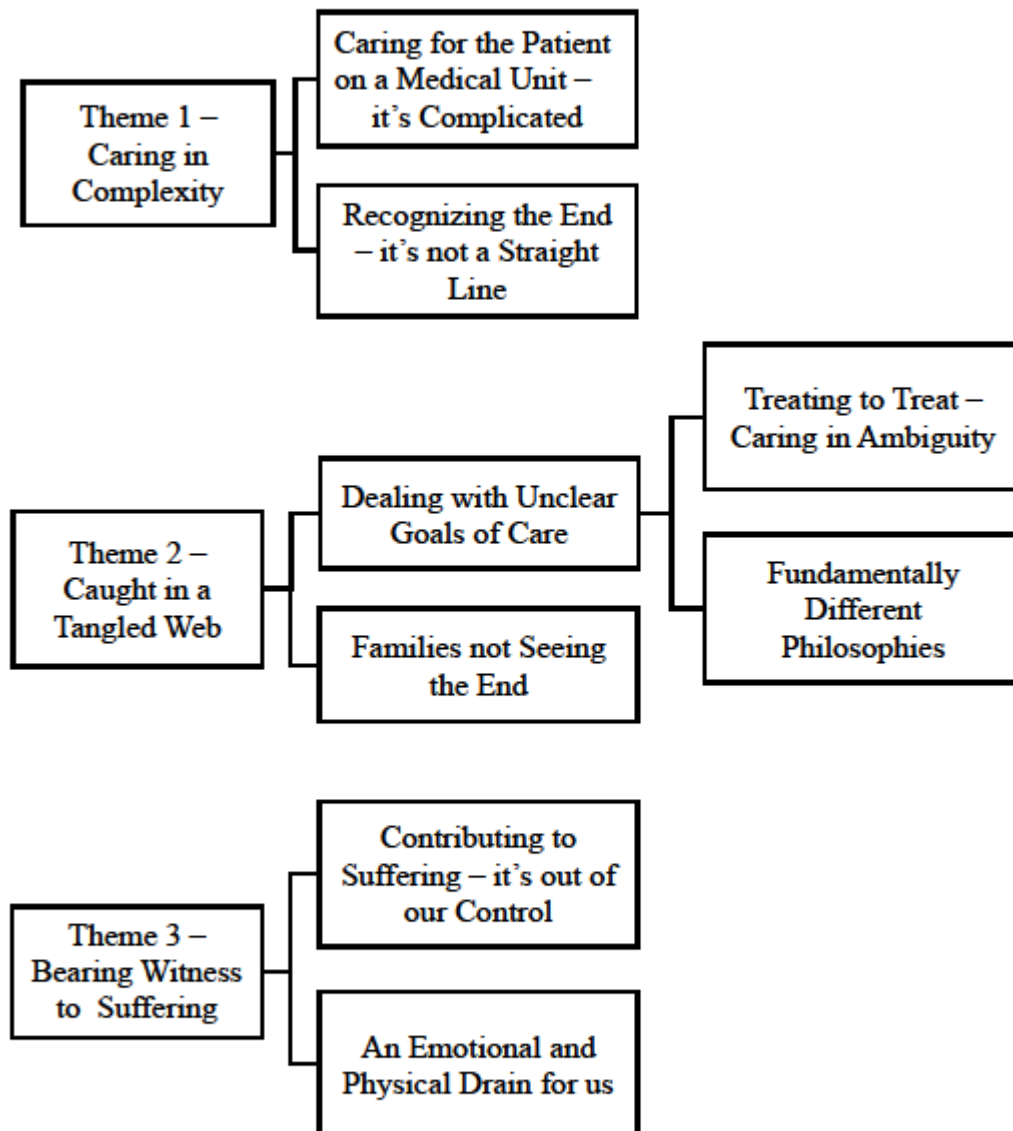
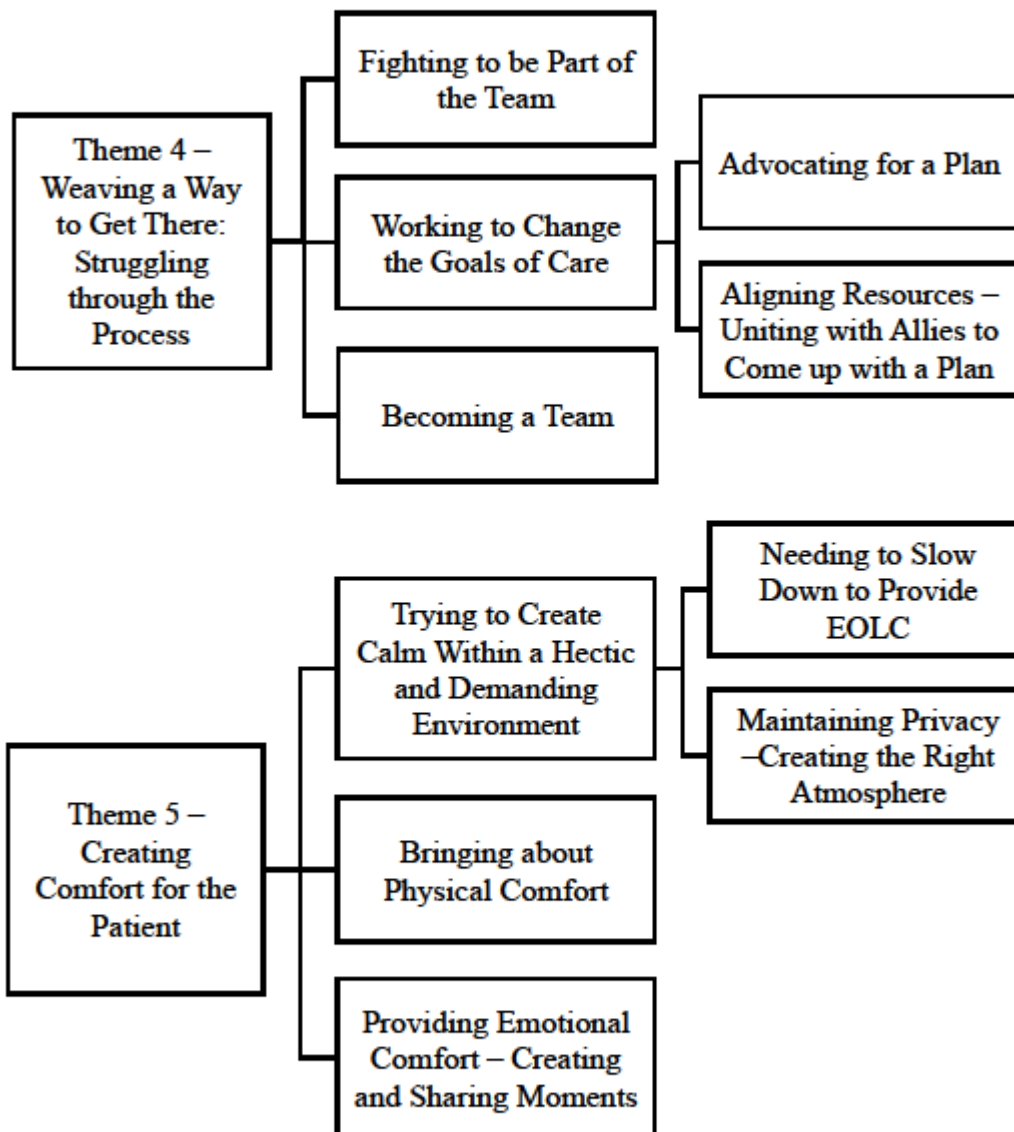
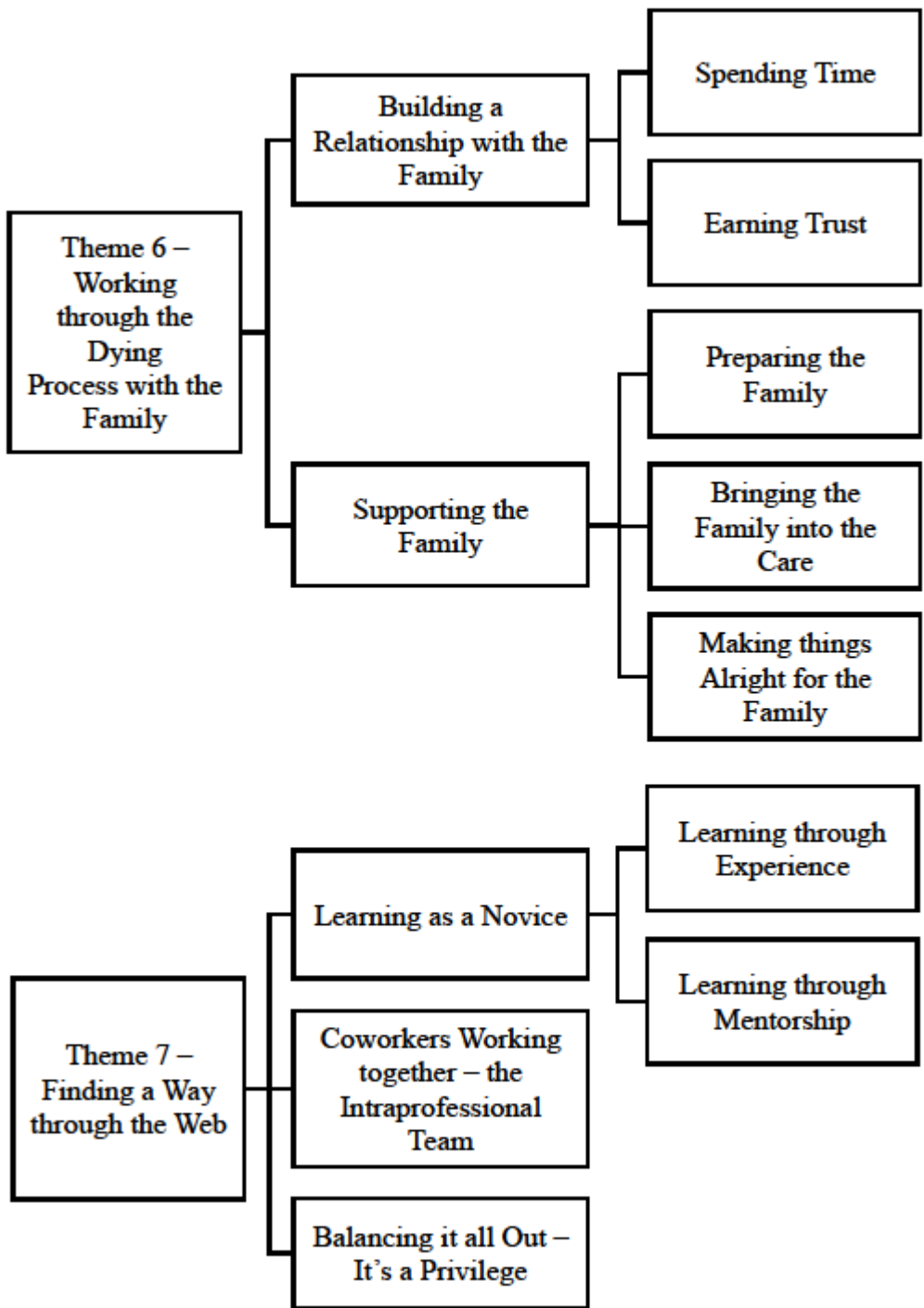


Figure 2: Organizational Schematic of Themes and Subthemes





Chapter 1: Introduction

Nurses working on inpatient hospital medical units draw from a broad base of knowledge and possess a diverse range of skills and proficiencies in order to care for patients who may present with any number of medical conditions. These nurses attempt to support and meet their patient's and family's needs during episodes of illness and hospitalization. In a busy, unpredictable environment, these nurses utilize their skills of flexibility and prioritization as they assess, plan, intervene and evaluate the care for multiple patients and their families as they progress along the path from illness to improvement, recovery, or end-of-life (EOL). During the course of their work, nurses on medical units function in a number of roles including collaborator, resource allocator, and communicator as they work to coordinate, organize and effectively manage care between multiple care providers, and within hospital processes and policies.

Like many nurses, my career in nursing began on a medical unit. Medicine is where I developed the foundation of my nursing knowledge and skills in an environment rich in variety, challenge and personal and professional reward. As a novice, I recall trying to resist feeling overwhelmed as I attempted to balance planned workload with unpredictable demands. The medical environment that began as my training ground as a novice, I soon recognized as the area in which I wished to remain and specialize over my career.

Over the years, I have developed a particular interest in end-of-life care (EOLC) as it is delivered in an acute care environment that has only increased in acuity and complexity. In my current role as nurse educator, I wanted to learn more about what it meant for nurses to provide EOLC on a medical unit, the obstacles to care, and what support nurses required to be able to assist patients and their families during this profound and emotional life event.

1.1 Background

With the advent of public health, a focus on healthier living, and improvement in medical therapies (Lynn & Forlini, 2001), Canadians are living longer. Since the early 1920s, the life expectancy of male Canadians has increased from 59 to 79 years and from 61 to 83 years for Canadian women (Statistics Canada, 2012b). Many elderly Canadians are living with one or more chronic illnesses (Canadian Hospice Palliative Care Association [CHPCA], 2014; Report of the Standing Committee on Health, 2012). Chronic illness, such as cancer, heart disease, cerebrovascular disease and chronic respiratory diseases, are attributed to roughly 70% of deaths in Canada (CHPCA).

Approximately 66% of deaths in Canada occur in hospital (includes deaths in residential and long term care institutions in Quebec) (Statistics Canada, 2009). Busy hospital environments focused on efficiency, routines, task completion and organizational policies and procedures, can make it difficult to effectively meet the needs of patients who are at end-of-life (EOL) and require palliative care (McDonnell, Johnston, Gallagher, & McGlade, 2002; Pincombe, Brown, & McCutcheon, 2003; Rogers, Karlsen & Addington-Hall, 2000; Wallerstedt & Andershed, 2007). Palliative care is an approach focused on improving quality of life (CHPCA, 2012); Canadian Nurses' Association [CNA], 2008b; Health Canada, 2009; Registered Nurses' Association of Ontario [RNAO], 2011; World Health Organization [WHO], 2007) and the relief of suffering (CHPCA; CNA; WHO), through the active management of symptoms (RNAO; WHO) for patients and families (CHPCA; Health Canada; RNAO; WHO) who are facing an actual or potentially life-threatening illness. Palliative care involves holistic patient and family care including the support of physical, psychological, emotional, social, cultural, spiritual, and practical care needs (CHPCA; Health Canada; RNAO, WHO). Palliative care can be initiated at

any point in an illness trajectory (from diagnosis to death), and can be provided concurrently with curative or disease modifying therapy, as part of chronic/progressive disease management, or terminal care (Meghani, 2004; Pereira & Associates, 2008).

While early conceptualizations of palliative care have been associated with providing care to individuals who are dying (Meghani, 2004), the concept of palliative care has evolved into both an approach and philosophy of care that is no longer seen in opposition to cure, but complementary to it (Ferris et al., 2013; Lynn & Adamson, 2003; Meghani; Pereira & Associates, 2008). EOLC is one aspect of palliative care with a specific focus on the final days and hours of life (RNAO, 2011).

Studies of hospital care have identified that EOLC could be improved (Costello, 2006; Dunne & Sullivan, 2000; Ferrand et al., 2008; Pincombe et al., 2003). Areas identified which needed improvement included: the management of symptoms (Ferrand et al.; Parish et al., 2006; Toscani, Di Giulio, Brunelli, Miccinesi, & Laquintana, 2005), access to written EOL protocols (Ferrand et al.; Parish et al.), recognition of patients facing impending death (Parish et al.), and the incorporation of palliative care principles within a curative approach (Clarke & Ross, 2005; Gardiner, Cobb, Gott, & Ingleton, 2011). There was also a tendency within hospital care to pursue aggressive/inappropriate interventions despite anticipation of death (Borbasi, Wotton, Redden, & Chapman, 2005; Ferrand et al.; Toscani et al.) With an increased number of deaths likely to occur in hospital medical settings, more needs to be known about the experience of nurses providing EOLC on these units.

1.2 Purpose of the Research Study

The purpose of this study is to seek to understand the lived experience of nurses on a medical unit providing EOLC to patients.

1.3 Objectives of the Research Study

The objectives of this study are:

1. To describe the experience of nurses providing EOLC on an acute medicine unit.
2. To identify which factors support and which factors hinder nurses in caring for patients who are dying.

Chapter 2: Literature Review

This chapter presents a review of the nursing literature on providing EOLC in non-critical care hospital settings. The PubMed and Cumulative Index to Nursing Allied Health Literature (CINAHL) databases were searched to obtain primary research and review articles focusing on nurses' perception, attitudes or experiences in providing EOLC to adult patients who were dying on inpatient units. No date limitations were placed as part of the search methods. Searches were restricted to English articles and adult populations (eighteen years of age and older). The primary goal of the literature search was to identify the current state of knowledge surrounding nurses' perceptions and experiences of EOLC in non-critical care areas. Studies conducted in critical care, oncology and specialized palliative care environments were excluded. Critical care environments were excluded due to the unpredictable and immediate nature of some deaths as well as the potential for complex decision-making related to the withdrawing of life support or other therapies unique to the critical care setting. Oncology and specialized palliative care environments were excluded from the search, as it was hypothesized that nurses working in these environments would be more frequently exposed to patients who were dying and would possess more specialized skills and knowledge in applying the principles of palliative care in their day to day work. Keywords used as part of the search included: dying, terminal care, terminally ill, hospice care, end-of-life, and palliative care. Keywords representing the setting of interest included: medical-surgical nursing, surgical ward/unit, medical ward/unit, neuroscience nursing, orthopaedic nursing, urology nursing, hospital and generalist.

Literature, organizational reports, position statements, and statistical data were also utilized as a means of providing a background including: a profile of patients seeking care on

medical units, the medical unit environment, nurses' work on medical units and what constitutes palliative/EOLC in that setting.

2.1 Patients Living and Dying with Chronic Medical Conditions

Advances in medical technology and therapies are allowing individuals to survive to achieve greater life expectancies, and as a result, chronic diseases have surpassed acute illness as the primary cause of death (Davies & Higginson, 2004; Statistics Canada, 2009) and account for approximately 70% of all deaths in Canada (CHPCA, 2014). Chronic illnesses such as malignant disease, heart disease, cerebrovascular disease, and chronic lower respiratory diseases (includes chronic obstructive pulmonary disease [COPD]) respectively make up the top four causes of death in Canada (Statistics Canada).

Unlike malignant disease, death from chronic, progressive, organ failure often follows an unpredictable trajectory (Lynn, 2001). Disease progression varies greatly with diagnosis and unique patient factors (age, health condition, co-morbidities, and extent of the disease) (Lewis, Heitkemper, Dirksen, O'Brien, & Bucher, 2010). Many patients living with end-stage organ failure (e.g. cardiac disease, COPD) experience acute exacerbations in their illness requiring hospitalization for aggressive medical therapies (Canadian Institute for Health Information [CIHI], 2007; Murray, Kendall, Boyd, & Sheikh, 2005). Periods of recovery may follow hospitalization; however, the patient's level of functioning and health gradually decline over a period of months to years (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Murray et al.). For patients and families accustomed to a prolonged pattern of illness, exacerbation, and improvement, death, when it occurs, appears sudden (Lynn; Lynn & Adamson, 2003). Predicting which exacerbation will eventually result in death is difficult (Lynn & Adamson; Pereira & Associates, 2008). The challenge for many health care providers comes in identifying and

diagnosing impending death for patients who are in the palliative stage of their disease for long periods of time (LeGrand & Walsh, 2010; Pereira & Associates).

In 2012, the estimated number of seniors (65 years of age or older) in Canada totaled over 5 million (14.9%) (Statistics Canada, 2012a), this number is expected to double to somewhere between 9.9-10.9 million (23-25%) by the year 2036 (Statistics Canada, 2010). According to evidence provided as part of the House of Commons proceedings, 74 to 90% of Canadian seniors live with one chronic condition; in another survey, 25% of Canadian seniors were reported to have two or more chronic conditions (Report of the Standing Committee on Health, 2012). With a rapidly aging population (CHPCA, 2014; Davies & Higginson, 2004), an increase in life expectancy, and presence of chronic illness and disability, the number of individuals requiring hospital services and the complexity of their care is likely to continue to grow (Physician Hospital Care Committee, 2006). A lack of community resources for chronic disease management and limited access to palliative care services means more individuals suffering from chronic, progressive illnesses will be admitted to hospital medical units to receive care (Physician Hospital Care Committee).

2.2 Nursing Care on a Medical Unit

Nursing care on medical units may be considered complex and challenging stemming from the inherent variety of patient conditions associated with this setting (Hanink, n.d.). Nurses must be prepared to care for patients with a wide breadth of diagnoses including heart failure, cancer and kidney disease (Hurst, 2011), who vary in age (18 to over 100 years of age), acuity (stable to life-threatening) and present with their own unique combination of comorbidities, disabilities and degree of functional capacity (ambulatory to bed ridden) (Canadian Association of Medical and Surgical Nurses [CAMSNS], 2008).

However, nurses on medical units are frequently caring for patients who are elderly. As compared to other adults, seniors are more frequent users of hospital, physician, continuing care and home care services (CIHI, 2011). At particular risk are the elderly who are frail, suffer from isolation, or have limited incomes or access to supports such as single (unattached) females, immigrant and rural based seniors (McDonald, 2011). For those seniors who require support to remain independent, many rely on formal (homecare) and informal supports (family caregivers/friends) to do so (CIHI). As these patients seek hospital care, nurses must take these considerations into account and address the need for additional physical, social, and financial supports as well as the capacity of informal caregivers.

Meeting the health care needs of patients on medical units is becoming more complex as patients are living longer (Lewis et al., 2010), with multiple chronic health conditions (Lewis et al.) and patients and their families as consumers have access to more information, new technologies and advances in medications and treatments than ever before. Nurses are required to assess and manage a wide variety of therapeutic technologies and interventions such as chest tubes, tracheostomies and wound therapies as a regular part of their nursing care (Hanink, n.d.; Hurst, 2011). Patients now on medical units would previously have been treated in intensive care settings (Hanink). It is becoming more common to see services such as telemetry monitoring (Hanink) and the use of step-down areas as part of medical unit care (Hurst).

Medical nursing, at times described as the foundation of nursing practice, is a complex and challenging specialty (Grindel, 2004; Hurst, 2011). However, unlike some specialties, medical nursing is not focused on one organ system, disease process or therapeutic procedure (Grindel). Nurses practicing on medical units must draw from an extensive knowledge base in order to provide care to patients and families (CAMSN, 2008; Grindel; Hanink, n.d.; Lyneham,

2013) and be able to prioritize multiple care needs. A nurse may be required to assess a patient as they are admitted to the unit, provide teaching to a patient newly diagnosed with diabetes, manage interventions for a patient experiencing respiratory failure, while preparing yet another patient for their discharge to home with community resources (Hurst). Against this backdrop, the medicine nurse must always be watchful for the “subtle changes” that forewarn an acute decline in condition or face a sudden, life-threatening emergency (Hurst; Fights & Lattavo, n.d.; Singleton as cited in Hanink).

With length of hospital stays shortening and the acuity of patients increasing, medical nurses face increased workloads as they attempt to provide the same degree of nursing care over shorter, intense periods of time (Munn as cited in Kreimer, 2008; Thomson, 2007). In response to the backlog of admitted patients remaining in crowded emergency rooms, and the limitations in access to long-term beds, community resources and other specialized services (rehabilitation, mental health beds) (Physician Hospital Care Committee, 2006), nurses on medical units face the additional pressure of trying to maintain an efficient flow of patients through the admission and discharge processes (Thomson).

In order to provide safe and efficient care, medical nurses regularly interact with, communicate and collaborate with a large number of specialty services, hospital departments and professionals as part of coordinating patient care. In addition, they must: negotiate a variety of staff with varying skills mix (registered practical nurses [RPNs], physician assistants), work with unregulated health care providers (orderlies, support staff, sitters), and adjust to unexpected changes in patient to nurse ratios in response to bed occupancies and availability of nursing staff (CAMSNS, 2008). Adding to the complexity of the patient care environment, medical units are often the centre of a large number of clinical placements requiring nurses to mentor/support a

high volume of learners such as medical students, medical residents, nursing students, allied health students, and new graduates (CAMSN).

2.3 Palliative and EOLC in the Medical Environment

Providing nursing care to patients who are in the advanced stages of their disease as well as providing EOLC for those who are dying is an integral part of care within the medical environment.

2.3.1 The palliative care philosophy.

The philosophical view of palliative care regards death as the natural conclusion of an individual's lifespan and therefore does not attempt to either delay or accelerate the dying process (Pereira & Associates, 2008; WHO, 2007). The palliative philosophy is built on the view of the person as a holistic being who has multidimensional needs, including physical, psychosocial and spiritual (CHPCA, 2012; Health Canada, 2009; RNAO, 2011; WHO). The goal underlying palliative care is to improve a person's quality of life through the relief of suffering, control of symptoms and support of both the person and their loved ones (family/friends) as they face the possibility of death (CNA, 2008b; CHPCA; WHO). The palliative approach to care is guided by this palliative care philosophy and uses a multidisciplinary, collaborative, team approach to skillfully assess, identify and manage the holistic needs of patients and families, to promote their comfort, and provide relief from symptoms or other forms of distress (Pereira & Associates; WHO).

Palliative care. Research has shown that patients with chronic progressive medical illnesses have needs which could benefit from a palliative approach to care. While modern representations of palliative care conceptualize it as appropriate care for patients living with chronic illness, historical depictions of palliative care as synonymous with dying and

dichotomous to curative care, continue to persist in today's practice setting and within the public perception creating a barrier to its early initiation. Initiation of palliative care can occur at any point during the illness continuum (diagnosis, to death) and can complement curative therapies (Ferris et al., 2013; Meghani, 2004). Current models of palliative care such as the Canadian Hospice Palliative Care Association's (CHPCA) model to guide hospice palliative care (Ferris et al.) advocate for the initiation of a palliative approach to care as early as the time of diagnosis or at the moment when patient/family has needs (physical, psychological, spiritual) that could benefit from palliative intervention (Davies & Higginson, 2004; Pereira & Associates, 2008). Palliative care strategies would become the focus in an individual's plan of care as disease-modifying therapies become less effective, or are no longer suitable or desirable (Pereira & Associates).

Patients with advanced medical illnesses often have holistic needs which are beyond the realm of the medical model to fully address and manage (Bacon, 2012). For example, individuals with non-malignant diseases (e.g. heart failure, kidney failure, respiratory disease) described increasing dependence (Fitzsimons et al., 2007), suffered from social isolation (Fitzsimons et al.; Murray et al., 2002), had limited access to resources and support (Fitzsimons et al.; Murray et al.) and felt that they were a burden to family (Fitzsimons et al) as their condition declined. A palliative care approach can begin to address the emotional, psychosocial, and spiritual needs that often accompany living with end-stage diseases (Bacon) as well as the possibility for advanced care planning.

EOLC. While a palliative approach to care can be initiated at any point along the illness trajectory, EOL addresses the period of time when an individual has entered the terminal stage of their illness and is approaching death. There is a lack of clarity in the literature surrounding the

term EOL which stems partially from its interchangeable use with palliative care, hospice care and terminal care, as well as the lack of consensus regarding the specific timeframe which constitutes EOL (Izumi, Nagae, Sakurai, & Imamura, 2012; RNAO, 2011). In some instances EOL may refer to the weeks and even months before death, other sources define this phase as encompassing the last days to hours of life (Izumi et al.; Pereira & Associates, 2008; RNAO). EOLC has its basis in the palliative philosophy of care and therefore shares in its principles such as a focus on maintaining quality of life as an individual approaches death (Lewis et al., 2010), a reduction of suffering, support of patients and families, and total patient care (physical, psychological, emotional, social, cultural, spiritual, and practical) (CNA, 2008b; Ferris et al., 2013).

2.3.2 Palliative and EOLC in the Hospital Setting

Several studies have been conducted to examine the perceptions of the quality of EOLC received in hospital from the perspective of patients and their families (Dunne & Sullivan, 2000; Heyland et al., 2005, 2010; Teno et al., 2004). These studies have identified unmet patient/family needs central to EOLC including deficits in pain and symptom management, communication, inclusion in decision-making, physician availability, privacy, and emotional support (Dunne & Sullivan; Heyland et al., 2005, 2010; Teno et al.).

A medical approach focusing on curative care can come into conflict with a palliative approach to care (Borbasi, et al., 2005; Davidson et al., 2002) and at times, patients' and families' wishes for comfort (Davidson et al.; Lynn et al., 1997). While modern conceptualizations of palliative care have grown to include a more diverse population of recipients than individuals living with cancer, in practice, patients dying with chronic medical illnesses such as heart disease and COPD have been found to receive formal, specialist palliative

care services less frequently (Borbasi et al.; CHPCA, 2014; Davies & Higginson, 2004; Murray et al., 2002; Tranmer et al., 2003) than patients with malignant disease. Borbasi, Wotton, Redden and Chapman (2005) found in a study related to situations when palliative care service referrals were made, that it was frequently too late in the dying process to improve the quality of dying. Heyland et al. (2005) observed that difficulties in determining when patients with progressive illness were at the EOL may have been at the root of why patients were not referred to specialist palliative services despite presence of symptoms. Due to difficulties in prognostication of the terminal phase of illness and a medical tendency to pursue aggressive therapies late in the dying process (Borbasi et al.; Ferrand et al., 2008; Toscani et al., 2005), medicine nurses, who are at the forefront of providing care to hospitalized patients at EOL, must at times do so without specialized palliative care services or physician support.

Nurses have expressed that they do not feel adequately prepared to provide EOLC (Dunn, Otten, & Stephens, 2005; McDonnell et al., 2002; Thacker, 2008; White, Coyne, & White, 2012), lack education on palliative care principles (McDonnell et al.), and have difficulties communicating with patients regarding death and dying (Betcher, 2010; Sasahara, Miyashita, Kawa & Kazuma, 2003). Studies describe nurses' feelings of frustration (McDonnell et al.), guilt (Costello, 2006; Pincombe et al., 2003), and failure (Costello), when they are unable to provide the quality or level of care they wish for patients at EOL.

2.4 Studies Examining Nurses' Experiences in Providing EOLC in the Medical Unit Environment

2.4.1 Quantitative studies.

Quantitative studies highlight the difficulties encountered by nurses in their provision of EOLC on general medical-surgical wards. McDonnell, Johnston, Gallagher, and McGlade (2002) used a self-administered questionnaire to study nurses' (n=147) perception of the quality of palliative care provided on 18 medical and surgical wards. Study findings revealed that while a majority of participating nurses (70%) viewed EOLC as an important aspect of hospital care, few (8%) felt that the hospital was a suitable environment to care for the dying. Barriers to EOLC included: nurses' lack of confidence in communicating with patients about death and dying, a lack of confidence in providing psychosocial care for families, the absence of a multidisciplinary approach to EOLC, and feeling unsupported by physicians, managers, and the organization. Nurses in the study also expressed feeling unprepared by their training and education to care for patients who were dying.

A study conducted by Parish et al. (2006) examining the EOLC received by patients on medical and surgical wards in a teaching hospital in Australia (using chart audit/nurse interviews) identified opportunities for improvement; only 45% of nurses believed that all of the patient's EOL needs were met. Researchers identified barriers to nurse-physician teamwork including nurses not feeling empowered to communicate with physicians regarding treatment plans and difficulties in accessing physicians overnight to speak with families. Chart reviews revealed nursing care to be particularly focused on the physical and symptomatic care of patients while there was a general lack of documentation of patient/family psychosocial and spiritual care

needs. Similar to the findings in the McDonnell et al. study (2002), nurses identified an interest for more education on palliative care topics and additional supportive resources.

Two quantitative studies used self-administered questionnaires to examine the relationship between various personal, professional, and environmental factors and their effects on providing EOLC such as: nursing autonomy and attitudes towards EOLC (Miyashita et al., 2007) and factors associated with difficulties providing EOLC (Sasahara, Miyashita, Kawa & Kazuma, 2005). Miyashita et al. (2007) found a correlation between positive nurse attitudes in caring for the dying and years of experience, presence of mentorship, and education. Sasahara, Miyashita, Kawa and Kazuma's (2005) study revealed a correlation between clinical experience and mentorship with fewer difficulties in communicating with patients and families at EOL.

2.4.2. Qualitative studies.

Eight articles detailing the findings of four qualitative (Clarke & Ross, 2005; Costello, 2001, 2006; Hopkinson, Hallett, & Luker, 2003, 2005; Thompson, McLement, & Daeninck, 2006a, 2006b) and one mixed methods study (Pincombe et al. 2003) were found which examined nurses' experiences or perceptions of providing EOLC to patients in non-critical care environments. The majority of the qualitative studies occurred in hospitals outside of North America including the United Kingdom ([UK] n=3) (Clarke & Ross; Costello, 2001; Hopkinson et al., 2003) and Australia (n=1) (Pincombe et al.); one study was set in Canada (n=1) (Thompson et al., 2006b). Nursing at EOL was examined through different methods including phenomenology (Hopkinson et al., 2003), grounded theory (Thompson et al., 2006b), and ethnography (Costello, 2001), and with different foci such as perceptions of quality of care (Thompson et al., 2006b), the type of care given at EOL (Pincombe et al.) and nurses' communication practices (Clarke & Ross).

Costello (2001) conducted an ethnographic study to examine the care of patients who were elderly and dying on three elder care wards in the UK. While the purpose of the study was to explore the EOL experiences of nurses and patients on these units, students (n=6), auxiliaries (n=19), and physicians (n=5) were also interviewed along with nurses (n=29) and patients (n=74). Participant observation (250 hours) was also performed as part of the research design. Costello identified three themes which highlighted barriers to the provision of quality EOLC including: nurses' focus on meeting the physical care needs of patients over psychosocial care, staff and physicians not communicating terminal prognoses to patients, and power imbalances between physicians and nurses. Costello found that despite nurses' proximity to patients, decision-making related to treating symptoms, disclosing prognosis, and determining resuscitation status was ultimately made by physicians. While not overtly challenging physicians' decisions, nurses reported symptoms to physicians in order to access medications and pressured physicians for do not resuscitate orders (DNR). The author observed that when disregarded, participants resorted to "passive aggressive" measures such as "non-cooperation" to achieve their ends (p. 65). Limitations of the study identified by the author included its exclusive focus on patients who were elderly and the heterogeneous nature of the three elder care wards included in the study (rehabilitation, acute assessment unit, continuing care unit). As part of a secondary article based on the original study's findings, Costello (2006) categorized nurse participant's descriptions of EOLC into what constituted "good" and "bad" deaths on hospital elder care wards (p. 594). "Good deaths" were classified as those which were expected, controlled, and had minimal impact on ward routines (p. 598). "Bad deaths" were described by participants as those deaths over which they felt they had little control: symptoms were not well managed, death was traumatic or undignified, and included those deaths which occurred

suddenly or too quickly for nurses and families to be prepared (p. 599). In this study, EOLC was described as “stressful” not only because of its ability to emotionally impact nurses, but it was made more difficult when the ward was lacking in material and human resources, including a shortage of support staff, fewer nurses on duty and the presence of agency nurses (p. 599).

Pincombe, Brown and McCutcheon (2003) conducted a study using a mixed methods design in order to obtain information on the type of EOLC patients received on acute care hospital units. This study took place on eight medical and surgical units in two teaching hospitals in Australia. The methods comprised non-participant bedside observations, which noted the type and duration of EOLC provided to patients, as well as interviews with 12 nurses. Findings were organized into three categories of factors which affected care: “the human factor”, “the organizational factor”, and “the environmental factor” (p. 82). The human factor referred to the individuals involved in, contributing to, or impacted by the EOL process. The human factors that facilitated EOLC included: the presence of family and the importance of teamwork between health professionals. Family members were described as helpful to nurses in EOLC since the family often tended to the emotional and physical needs of the patient, particularly when nurses felt they did not have the time to provide psychosocial care. Human factors which acted as barriers to EOLC and impeded effective teamwork included hierarchical decision-making and the lack of information sharing between health care professionals. The organizational factor theme encompassed the hospital structures, routines, or rules which organized, regulated or influenced EOLC. Organizational factors which could act as barriers to EOLC included: hospital routines that were focused on task completion, medical rounds and restrictive policies such as visitation rules. The environmental factor theme addressed the impact that the physical environment had on the provision of EOLC and encompassed the “physical design”, “layout”

and “ambiance” of the unit (Pincombe et al., p.84). Environmental factors identified as barriers included the presence of noise, odours and activity on the unit as well as the practice of placing patients in side rooms for privacy which inadvertently isolated the patient.

Clarke and Ross (2005) conducted an exploratory study into nurses’ experiences in communicating about EOL issues with patients who were elderly and dying. Two medical units and one palliative care unit (PCU) in a general hospital in the UK were selected as the setting and data were collected utilizing both a focus group format and follow-up individual interviews. Twenty four participants were enrolled in the study including nurses, nursing students and support workers. Separate focus groups were held with participants from the PCU and medical units. The authors analyzed the interview data examining the commonalities and differences between individual participants as well as between the two practice environments. The barriers to nurses’ communicating with patients regarding EOL issues were found almost exclusively within the medical units. The authors associated these barriers with a “culture of care” on the medical units which lacked the “openness and support” required to facilitate EOL communication (Clarke & Ross, 2005, p. 39). Obstacles to communication identified within the medical units included the following: patients who were unaware or in denial of the terminal nature of their condition; lack of time due to workload and competing tasks; a general absence of privacy; and an emphasis towards the completion of nursing tasks rather than patient communication. Nurse-physician related barriers to communication included: differing views of goals of care (comfort versus cure), physicians not providing enough or too much information to patients about prognosis, and nurses not being informed when physicians communicated the results of a poor prognosis to patients. Participants from both practice environments described learning to communicate with

patients about death and dying through clinical experience and in watching more experienced/specialized palliative care nurses' interactions with patients.

There were several limitations which impacted the generalizability of the findings of Clarke and Ross' study (2005). The authors did not provide a description of the setting, context, or sample characteristics for their study. While nurses were identified as the group of interest within the study purpose, the authors did not provide a rationale for the inclusion of students and support workers as part of the sample. The experiences and perceptions of students and non-professional support staff may have brought forth different reflections within the study findings due to the different levels of training, experience, communication skills and perceived role in EOLC than if the sample had consisted of registered nurses only. A focus group format may have also impacted the free expression of ideas and participation of members particularly as these groups included the matrons, sister/charge nurses, and a heterogeneous group of individuals. The comparison between two settings of care was useful for exploring and examining the similarities and differences between these two environments of practice. However, a limitation of this was that it did not allow for a deeper exploration into the specific experiences of nurses on medical units as its own entity.

Hopkinson, Hallett and Luker (2003) conducted a phenomenological study of 28 newly qualified nurses from eight acute medical units in the UK. The purpose of the study was to understand from these novice nurses' perspectives what it was like to care for patients who were dying and to build a theory of how nurses could be assisted in providing quality EOLC. Participants in the study described working in an environment of tension resulting from the imbalance between the nurse's idea of the care patients who were dying should receive, the unknown nature of the dying process, not feeling prepared, and the realities of providing care in

a challenging hospital setting. Nurses described tension arising from the lack of time to manage the needs of patients at EOL while trying to meet the demands of the unit and managing the care for other patients. Participants also experienced tension when patients or their families were perceived to be suffering without need. Strategies used by nurses to prevent or relieve tensions (anti-tension) included the presence of supportive relationships and controlling emotional attachment to patients. One limitation of the study was that the findings were mainly presented focusing on the participant's reactions, reflections, desires and feelings as they encountered different situations in EOLC rather than on the care itself or processes of care. Despite the aim of the study to "develop an understanding of the care" provided at EOL (p. 525), the relationships that impact the experience and quality of EOLC were mentioned superficially (e.g. the participants' relationship with family and other nurses) or not mentioned at all (relationships with physicians and other health care professionals). The impact of these relationships, communication, participation in decision-making, or a specific exploration of the effect of the environment on care would have provided a deeper understanding of the experience of providing EOLC. The authors' objective of building a theory utilizing a phenomenological approach was also a limitation given the study design.

In a subsequent article, Hopkinson, Hallett, and Luker (2005) addressed some of these limitations by further expanded upon the findings of their original study to describe a model for how newly qualified nurses cope when caring for patients at EOL. The authors identified that helpful relationships (colleagues, relatives, patients), resources (information, shared decision-making), experiential learning, controlling emotional involvement with patients, measuring performance, use of anti-tensions and revising personal perceptions of the ideal death all assisted

with nurses' ability to cope. However, the building of a model as a result of a phenomenological exploration of nurses' experiences is a limitation given the approach.

Thompson, McClement and Daeninck (2006b) undertook a grounded theory study of 10 nurses from four acute care medical units in Canada to understand and develop a theory of the processes and behaviours used by nurses to provide quality EOLC. The main barrier to providing EOLC identified in this study lay in the fact that nurses were "being pulled in all directions" on the medical unit while trying to provide care for the dying (p. 169). The central theme of the study "creating a haven for safe passage" unified the processes of how nurses attempted to overcome this barrier to their provision of quality EOLC (p. 172).

Creating a haven for safe passage occurred through the employment of different nursing strategies and actions and was grouped into four sub-processes. The first sub-process, "facilitating and maintaining a lane change", described how a shift from curative care to active palliation needed to occur in order to enable quality EOLC (p. 172). The transition to comfort care could be hindered depending on the degree that patients, family, nurses and physicians acknowledged that the patient was dying. Participants expressed frustration when patients who they felt required EOLC received aggressive medical treatments. "Getting what's needed" described how participants often acted in the role of advocate in order to obtain what was needed to meet the physical needs of their patients (p. 173). "Being there" emphasized the importance of providing an emotional and physical presence to families of patients at EOL (Thompson et al., 2006b, p.173) and "manipulating the care environment" described how participants attempted to alter the environment to provide privacy. Other study findings included the importance of nurse-physician relationship in "facilitating and maintaining a lane change" and in the nurse being able to successfully advocate for "getting what's needed" (p. 175). Two limitations identified by the

authors included the lack of male participants in the study, and that the majority (eight of the 10) of participants were recruited from a hospital with few palliative care resources (one clinical nurse specialist in palliative care and no in-hospital palliative care team) which could affect the degree of support nurses, physicians, families and patients would receive on these units and hence participants may have experienced additional barriers in caring for patients at EOL in this environment. Another limitation of this study, given the chosen methodology, was its relatively small sample size; studies utilizing the grounded theory tradition typically have sample sizes of 20 to 30 participants (Polit & Beck, 2012).

A secondary article was published from the findings of this original study which focused exclusively on the sub-process of “facilitating and maintaining a lane change” (Thompson et al., 2006a, p. 91). The authors describe how participants utilized advocacy and education of the family as means of bringing about a lane change from curative care to EOLC. Barriers to obtaining a shift in the goals of care were classified as “medical factors”, “patient and family factors”, and “system factors” (p. 93-94). Medical factors related to the difficulty in prognosticating when patients with chronic illness had reached a terminal stage as well as the perceived reluctance of physicians to forego curative treatment. Patient and family factors included the age of the patient, lack of understanding of the nature of palliative care, unrealistic expectations, and denial regarding the terminal condition. System factors involved the lack of a palliative care philosophy on the medical units and difficulties encountered by nurses when working within an environment strongly influenced by a medical model of intervention. In both publications, participants identified the importance of providing an emotional and physical presence to families of patients at EOL and in removing environmental barriers to care (Thompson et al., 2006a, 2006b).

2.5 Summary

From a review of the literature some of the difficulties and barriers experienced by nurses while trying to provide EOLC on a medical unit were identified. Nursing care on medical units is challenging related to the diversity of patients, fluctuating acuity, and complexity of care needs of these patients. The demands related to the health care system, the routines of care, and the physical environment of the hospital has been shown to impact the nurses' ability to provide quality EOLC. In addition to environmental barriers, studies highlight the ineffective communication practices and the absence of a team approach which can impede care in these non-critical care settings.

The majority of the qualitative studies in non-critical care environments have been conducted outside of North America and were likely impacted by the differing contexts of care, unit structures, interprofessional relationships, and health care systems. The qualitative research studies that have focused on nurses' experiences in providing EOLC on medical inpatient units have to date focused on the perspectives of newly qualified nurses (Hopkinson, et al., 2003, 2005), nurses working on elder care wards (Costello, 2001, 2006), or on specific aspects of caring for the dying such as communication practices (Clarke & Ross, 2005) or quality of care processes (Thompson, et al., 2006b). In focusing on one particular aspect of the dying process, specific patient population, degree of nursing experience, or the inclusion of non-professional staff, individual studies to date have provided a limited view of the experience of nurses providing EOLC to the patient who is dying on acute medical units.

With the majority of deaths occurring on hospital medical-surgical units (McDonnell, et al., 2002; Thompson et al., 2006b) more needs to be known about the overall EOL experience of nurses practicing in these areas. There is a gap in our understanding of what it means for nurses

to care for patients at EOL in the context of an acute care medicine unit, how care is managed within an environment geared towards acuity, what are the facilitators and barriers to care and how best to support nurses in this demanding environment.

Chapter 3: Methods

An overview of interpretive phenomenology as both a philosophical stance and a research approach in guiding this study will be provided as well as a description of the sample, setting, and methods used to collect, analyze and ensure the trustworthiness/rigor of the findings.

3.1 Research Design

The focus of this study is to describe nurses' experiences of providing EOLC as it is situated and lived in the context of a medical unit. Studies in search of situated meaning through the perspective of the participant's experiences are best studied using a phenomenological philosophical perspective. Specifically, interpretive phenomenology using van Manen's (1990) approach has been used to guide this study as it moves beyond a description of how a phenomenon appears, to uncover and understand the deeper meaning of the experience as expressed through language and text.

Phenomenology has its roots within the constructivist and human science traditions (Fjelland & Gjengedal, 1994; Polit & Beck, 2012; van Manen, 1990). Phenomenologists view reality as a subjective, changing, and individually constructed experience (Polit & Beck; Reiners, 2012; van Manen). According to van Manen (1990), phenomenology as human science espouses a philosophical view of human beings as conscious beings who purposefully act on and in their world "by creating objects of meaning" (products of human work), which express their existence in the world (p. 4).

3.1.1 The underpinnings of phenomenological thought.

While Husserl, often viewed as the forefather of the phenomenological philosophy, conceptualized phenomenology as a descriptive process, Heidegger, a student of Husserl, moved phenomenology beyond the realm of description into interpretation (hermeneutics), to discover

the meaning and significance within a human experience (Plager, 1994). Phenomenology is interested in the study of human beings whom Heidegger (1962) describes as “Dasein”. Dasein refers to that entity (or being) that is capable of inquiring into the meaning of its own being (or existence) in time (Heidegger, 1962). To interpret the meaning of Dasein, one must examine human experience in its “everydayness” or “averageness” (Heidegger, p. 69). Van Manen’s (1990) approach, based on Heideggerian tradition, provides the methodological lens for this study. Van Manen describes hermeneutic phenomenological research as the study of a person’s lived experience (the person’s reality as it is immediately experienced in the world), in order to obtain a deeper understanding of the essence or meaning of these everyday experiences.

Human beings experience their “lifeworld” (world of lived experience) as it is affected by time, body and context and include: spatiality (lived space) as the experience of how a space makes us feel; corporeality (lived body) as our physical presence in the world, temporality (lived time) referring to time as it is subjectively experienced, which is affected by our past, present and future; and relationality (lived human relation) as our relationships with others (van Manen). As a means of exploring the participant’s lifeworld, participants were encouraged to recall and share their remembrances and stories of providing EOLC as they were lived in the medical unit environment. Throughout the data collection and analysis process, the researcher sought to gain an understanding of how the participants felt within the environment, their perception of space, and how they moved through their work. Particularly in relation to EOLC, the nurses’ sense of the passage of time, their changing perspectives of EOLC over their career and personal life, the cultural norms and relationships with others in providing this care was of interest.

3.2 Researcher Assumptions Regarding Nursing Care at EOL on a Medical Unit

The role of the researcher within the interpretive phenomenological approach is not as an impartial observer, but rather, as an active participant. Through interactions with participants, the researcher begins the process of mutually constructing understanding from these interpretations (Reiners, 2012; van Manen, 1990). While the researcher's background in medical nursing did provide a reference point for nurses' work in general and created a common ground for building trust and entrée into the participant's world, the researcher was cognisant to focus the research and interviews on the context of the participant's lifeworld. Therefore the researcher focused on seeking deeper meaning during the interview process by using questions to probe reflections made by participants without leading the conversation (Polit & Beck, 2012).

Prior to entering the research process, researchers often possess a degree of knowledge, preconceived notions and beliefs about the phenomenon of interest which they wish to understand. The presence of unacknowledged preconceptions may unconsciously influence the interpretation of the texts (Benner, 1994; van Manen, 1990). Therefore it is important to make explicit the researcher's assumptions and presuppositions prior to data collection/analysis (van Manen). This self-reflection is done to assist the researcher to become aware of their own beliefs in order to consciously limit their insertion into the data analysis (Benner; van Manen) and encourage transparency. The researcher's assumptions regarding nursing care at EOL on a medical unit included the following:

1. Nursing care at EOL is focused on the needs of the patient.
2. A patient's family is influential in the type of medical and nursing care received by the patient and in making treatment decisions.
3. Nurses want to ensure that patients are comfortable at EOL.

4. EOLC in a hospital environment is challenging for nurses due to: prioritization of acuity, workload, time constraints and the fast pace of care.
5. Many patients who are at EOL do not have advanced directives and/or have not been explicit with family members regarding their treatment wishes.

3.3 Sample

A purposive sample of 10 registered nurses (RNs) working on two medical units in a tertiary care teaching hospital was selected for this study. Phenomenological studies often have small sample sizes; frequently less than 10 participants (Polit & Beck, 2012). The final sample size for this study was influenced by the quality and depth of the experiential narrative material (data) (Polit & Beck; van Manen, 1990). Sampling continued until commonalities within the data were revealed through thick rich descriptions with numerous comments and examples (Munhall, 1994).

3.3.1 Eligibility criteria for participants.

Inclusion criteria were selected in order to allow the majority of RNs on the study units the opportunity to participate, while ensuring that only those RNs with experience with the phenomenon of interest were enrolled. Participants were required to meet the following inclusion criteria:

1. Be a Registered Nurse (RN) employed full time or part-time on one of the two study units,
2. Have been employed a minimum of six months on either of the study units,
3. Have experienced at least one death in the medical unit environment,
4. Be English speaking.

A minimum six month employment on the unit was required to ensure exposure to EOLC. This timeframe was chosen based on the researcher's experience as a nurse educator orienting new staff. While RPNs were also an integral part of the unit staff, enrolment was restricted to RNs to create a more homogeneous sample and avoid any differences that may occur from level of education, scope of practice, skills mix or the types of patients normally cared for by this group of professionals. Within this thesis, the term nurse will refer exclusively to RNs unless otherwise specified.

3.3.2 Recruitment.

Prior to beginning the study, the researcher met with the program director for medicine, the clinical manager of each unit and the nurse educator to explain the aims, purpose and methods of the study, to seek approval, and to determine the best approach for making contact with staff while minimizing disruption in unit routines. Written consent from both clinical managers and the medicine program director were obtained as part of the ethics approval procedure. Written approval for this study was obtained by the Research Ethics Board of the hospital prior to proceeding with recruitment activities. Nurses were recruited to the study through use of flyers which were posted on the units and left in general meeting rooms. These flyers, available in English (see Appendix A) and in French (see Appendix B), advertised the purpose and aims of the study, a request for RNs who met the inclusion criteria to volunteer to be interviewed, and contact information of the researcher. Recruitment also occurred as a result of several presentations made by the researcher to RN staff. Nurses who were interested in taking part contacted the researcher in person, by telephone and by email and were provided information on the study, what participation entailed, and if they wanted to participate, scheduled an interview.

Prior to commencing the interview, participants were provided two copies of the combined information sheet/consent form (see Appendix C and D) for review. Once the participant had read the information sheet/consent form, eligibility was confirmed by the researcher, any questions were answered, and both consent forms were signed by the participant and researcher, with one copy given to the participant. A demographic form was then presented to the participant (see Appendix E) in which data such as age, years of experience in nursing, years of experience as a RN on a medical unit, length of time on the specific unit under study and recent education in palliative care were collected. The participant was asked to select a pseudonym that would be used for the purpose of the recorded interview, transcripts and reporting of the findings. Of particular note, two participants selected the same name (Ann and Anne).

3.3.3 Participant characteristics.

Ten nurses participated in the study; three male and seven female. Demographic data was grouped in order to maintain the anonymity of participants since it was possible to distinguish individual participants based on the original ungrouped data. Nine of the nurses were recruited from Unit A, and one from Unit B; the researcher could not discern a rationale for the difference in numbers of enrolment between units. Participants ranged in age from 23 to 54 years with a median age of 43.5 years. Years of experience spanned from 11 months to 27 years with a median years of experience of 11.5 years. The length of time of employment on the unit ranged from 11 months to 26 years with a median duration of employment on the unit of nine years. With respect to educational preparation, four nurses were diploma prepared and six nurses possessed a bachelor's degree in nursing. Four nurses had attended a palliative care course within two months of their interview taking place.

3.4 The Context of Care

This study was conducted at a 1149 bed, multi-site, tertiary care teaching hospital located in a large urban city in Ontario which provides health care services to over 1.2 million people. This academic health center employs over 11, 000 staff and supports a large number of learners including over 4000 residents, fellows, medical students and nursing students. Patient care is guided by an interprofessional model of service delivery in which a diverse group of health care professionals share their expertise in order to work collaboratively to provide the patient with a coordinated, cohesive care experience.

3.4.1 The medical units.

Two medical units were selected as the setting for this study. Medicine units A and B are sister units located in close physical proximity to one another. Allied health professionals and physicians often move fluidly between these units. Unit A has 31 beds and includes an additional six bed step-down monitored area embedded within the unit. The step-down area, while located physically within the confines of unit A, is sectioned apart from the unit behind a wall and is accessible through two sets of doors. Patients in the step-down area often require cardiac monitoring, medical intervention and observation to a degree that cannot be provided on the medical unit, however, their level of acuity has not reached the point of requiring admission into a critical care unit. Unit A also has designated beds for patients diagnosed with acute stroke and two private rooms that can accommodate chronically ventilated patients. Unit B has 37 beds that accommodate both general medicine patients and patients admitted under a family medicine service. There are also two beds that can accommodate chronically ventilated patients as required. The study units are staffed with both RNs and RPNs, however, care in the step-down area of Unit A is provided by two RNs and an orderly.

Allied health professionals designated to work on the units include physiotherapists, an occupational therapist, and a pharmacist. To meet the varied psychosocial, emotional, physical and medical needs of patients and families, the inclusion of multiple care providers and the use of various clinical supportive services/consulting teams are often required. In addition to physician medical consultations (e.g. cardiology, respirology, neuropsychology, etc.) other supportive consulting services, health professionals, and community partners commonly seen on the medical units include the rapid response team, the inpatient palliative care consult service (PCCS), a speech language pathologist, spiritual care, a registered dietitian, a registered respiratory therapist (RRT), the acute pain service, diabetes consult nurses and a community care access center (CCAC) case manager.

Rapid response team. One of the consultation services available to support the medical management of patients experiencing an acute decline is the rapid response team commonly referred to as the RACE (Rapid Assessment of Critical Events) team. The RACE team is an interprofessional team consisting of a critical care physician, intensive care nurse and a RRT. The RACE team's services are available to all inpatient care areas outside of the intensive care unit. Referral may be initiated by any clinician such as a nurse or physician. A set of physiologic indicators of acute decline are used to help guide clinicians in identifying when a referral may be beneficial.

Palliative care consult service. The hospital setting where this study took place did not have a designated inpatient unit for patients who required active palliation. Patients at EOL are admitted to any inpatient unit or under any physician service in the hospital. The PCCS at the study site, consists of three physicians, four consult nurses, a social worker and an advanced

practice nurse. The role of the PCCS is to provide specialist expertise to the referring physician team and nurses, as well as support to patients and families.

Services provided by the PCCS include recommendations for symptom management, information regarding community palliative care resources, and the provision of professional education. Consultation to the PCCS occurs through a formal referral process initiated by the treating physician team. Nurses and other health care professionals are not able to self-initiate a referral to this service.

3.4.2 The patients on medical units.

Patients admitted to medical units A and B are adults who are often older (median age 71 years (personal communication with hospital performance measurement analyst, November, 2013) and possess multiple comorbidities such as diabetes, heart failure (HF), renal failure, peripheral vascular disease and dementia. Patients with chronic conditions often have multiple re-admissions. They may present with any number or combinations of needs, including social, financial, mental health, rehabilitative, medical, functional, and intellectual. Over time, as a patient's functional status declines, nurses may witness a patient progress from independent living, to requiring admission to a long-term care facility and eventual death.

Patients are admitted to these units almost exclusively through the emergency department and have come from locations such as home, retirement homes, long-term care institutions, group homes, correctional facilities, mental health facilities or from no fixed address. Patients may also arrive on medical units as a result of within hospital transfers. Transfers commonly occur between the intensive care unit (ICU) and the medical units. Patients who die on these medicine units often do so after acute, aggressive treatments are no longer effective, sometimes

after multiple admissions in and out of the ICU or transfers in and out of the monitored step-down area within unit A.

There are three levels of resuscitation (code status) a patient could receive at the institution where this study was conducted. These levels of resuscitation are referred to as a category status and include: category status one which represents full medical treatment, cardiopulmonary resuscitation (CPR) and admission into a critical care area if required; category status two includes full medical treatment, no CPR and an admission into a critical care unit if necessary; and category status three entails full medical treatment, no CPR, and no admission into a critical care unit (this does not restrict admission into a monitored step-down area). A category status three level of resuscitation may be ordered for patients under curative treatment plans or patients with EOL goals of care.

3.4.3 Physician team structure.

The medicine physician teams are composed of an attending staff physician, a senior medical resident, three to four junior residents, two to three medical students and a liaison nurse. Medical students rotate through the medical service every six weeks, residents change service every four weeks and staff physicians can switch over at any time based on previously arranged schedules.

Staff physicians provide oversight of patient care, supervision of residents and medical students, and monitoring of team function. Senior residents provide guidance to residents and medical students through facilitation of rounds, establishing the plan of care for patients, and being a resource for patient care or team issues. Medical students and residents are assigned to patients on service and are in charge of assessing patients daily and managing their medical care.

3.4.4 Nursing model of patient care delivery.

The nursing model guiding clinical practice at this institution is organized around three categories of personnel who provide direct patient care; RNs, RPNs and unregulated care providers such as orderlies. This care delivery model is structured upon guiding principles to create a system of layered supports for nursing personnel providing direct care. For example, in accordance with the model of nursing care, an expert RN is formally assigned in the role of Clinical Nurse Expert (CNE) every shift. Direct nursing care focuses on providing safe, competent care; continuity between care providers; respecting cultural beliefs; inclusion in decision-making and ongoing communication and prompt information sharing. This nursing model is meant to benefit nursing practice by increasing professional autonomy, accountability, and the making of patient care decisions (within scope of practice) in collaboration with patients and families.

3.5 Data Collection

Data collection occurred through individual, face-to-face, in-depth interviews which were conversational in nature (Polit & Beck 2012). All interviews were audio-recorded in order to maintain an accurate record of the interview data. Interviews were conducted by the primary investigator and lasted from 14 minutes and 50 seconds to one hour and 44 minutes in length. All interviews took place within the confines of the hospital in numerous locations including a lounge, office, or conference room where privacy was ensured and interruptions minimized.

The interview began with a broad, open-ended question that related to the aims of the study: “Can you tell me what it is like for you to care for a patient who is dying on your unit?” Participants were prompted to reflect on and describe a specific death on the unit, which was meant to keep the narrative concrete, and provide a close account of the “experience as it is

immediately lived” (van Manen, 1990, p. 67). In order to explore the experience in greater depth, and to facilitate understanding directed at meeting the aims of the study, prompting questions included: “What are some of the things that make it easier for you to care for dying patients?” “What are some of the things that make it more difficult for you to care for dying patients?” “How do you feel when you are looking after dying patients on your unit?” (Refer to interview guide, Appendix F).

Field notes were used to enhance data collected during the interview process by making mention of details that could not be captured though audio-recording such as non-verbal communication and the interview setting (Morse & Field, 1996). Field notes were documented in a private area immediately after each interview. Data collected within these notes included: observations made during the interviews, the context of the interview, interviewer thoughts, participant behaviours and methodological notes evaluating the interview process including strategies for future interviews. The content of field notes were not included as a formal part of data analysis, however, these field notes were reviewed prior to and during analysis of transcripts in order to situate the interviews within the context they were recorded thereby enriching the meaning of the data.

3.6 Data Analysis

Obtaining insight into the essential meaning of a phenomenon is achieved through a process of reflection, clarification, making the underlying meaning of the lived experience clear and communicating this structured meaning through text (van Manen, 1990). Thematic analysis is a process of insightful “invention”, “discovery”, of “seeing meaning” and identifying the structures that make up the essential experience under study (van Manen, p.79). Interview transcripts were read, reflected on and analyzed in order to capture the participants’ experience

of caring for patients who were dying on a medical unit. Van Manen's (1990) three approaches to isolating thematic statements were used to analyze interview material. The first approach, the "wholistic or sententious approach", involved thinking about the text as a whole and trying to create a phrase that embodied the essential meaning of text as one entity (van Manen, 1990, p. 93), which was done with the thesis supervisor after each interview was transcribed. The second approach, "the selective or highlighting approach", involved reading the text several times, in order to isolate by highlighting, underlining or circling, those phrases that were revealing or provided an essential component to the experience under study (p. 93). In the third approach, or "the detailed line-by-line" approach, every sentence was examined to determine what the sentence revealed about the phenomenon (p. 93). Through multiple readings of the transcripts, words were circled, underlined and notations made in the margins which reflected key words or observations within the participants' narratives. Revealing statements were then collected and sorted into folders and re-examined until the beginnings of themes and subthemes began to emerge. These subthemes were then reflected upon and examined until titles were refined and quotations which supported these themes were gathered. The relationship both within and between themes were analyzed until an integrated and comprehensive description and underlying essence of the experience of participants was revealed.

3.7 Strategies to Ensure Rigor/Trustworthiness

The researcher employed a number of strategies throughout the study to ensure trustworthiness (rigor). Lincoln and Guba (1985) cite criteria to establish the trustworthiness of qualitative studies namely; credibility, confirmability, dependability and transferability.

3.7.1 Credibility.

Credibility can be described as the degree of confidence a research consumer has in the truth of the data and ensures that the findings reflect the participants' lived experiences (Lincoln & Guba, 1985). One method of increasing or enhancing credibility involves the use of member checking to confirm the validity of the findings with the participants. A second interview was scheduled with eight of the 10 participants in order to have them review a summary of the study themes and findings and discuss how these findings reflected their experiences. Credibility was also enhanced as the research team in this study consisted of experts in qualitative methods, particularly phenomenology.

3.7.2 Confirmability.

Confirmability refers to the extent to which the findings of the study originate from the experiences of the participants and not as a result of researcher supposition or bias (Lincoln & Guba, 1985). Researcher's assumptions about the phenomenon of interest were made explicit within the methods of this study as a means of holding them in check and maintaining neutrality in the analysis of the data. Confirmability was also ensured by having the thesis supervisor, an expert in qualitative data analysis, read all the transcripts and assist in the development of the themes. The themes from the analysis were verified and agreed upon by the thesis committee all of whom are experts in qualitative data analysis. Quotes from the participants were used to explicate each theme, thus providing the reader with how the themes related to the participants' experiences.

3.7.3 Dependability.

Dependability relates to the degree that data is considered to be stable over time and reproducible under comparable conditions (Lincoln & Guba, 1985). In order to allow for transparency and replication of the process that led to the study's findings, an audit trail was maintained outlining the decisions and actions made by the primary investigator during the research process. An audit trail of all decisions related to data analysis as well as methodological decisions was kept by the researcher. Sandelowski (1986) contends that a study and its findings are dependable when another researcher can clearly follow the decision trail used by the researcher. Methods of increasing dependability of the audio-recorded material employed by the researcher included: privately reviewing the audio-recordings for sound quality and completeness soon after the interview (Lincoln & Guba, 1985), transcribing interviews verbatim, and verifying the content of transcripts to the audio-recording for accuracy.

3.7.4 Transferability.

The term transferability relates to the degree to which a study's findings can be applied to similar groups or within other settings (Lincoln & Guba, 1985). Demographic data was collected in order to provide a description of the sample characteristics to assist readers in determining the transferability of the findings (Lincoln & Guba). Through a detailed description of the study's setting, contextual information, and participant characteristics, the consumer can reach their own conclusions (Lincoln & Guba).

3.8 Protection of Human Rights

Written approval was obtained from the hospital's research ethics board and the University of Ottawa's research ethics committee prior to beginning the study. Entry into the study units was obtained through the managers and educator of the units and their permission was obtained prior to posting information on the units.

Participants were provided a combined information sheet/written consent form (see Appendix C and D) on the study explaining their rights, the purpose/aims, risks/benefits of the study, what participation would involve, and information on confidentiality, storage, and destruction of interview material. The interviewer reviewed the information sheet/consent form with participants and answered questions prior to the participant signing the consent. Participants were made aware that they could choose not to answer any question and had the right to withdraw from the study at any time without negative impact on their current or future employment at the hospital.

Participant's identities and data were kept confidential. Anonymity was maintained through use of a pseudonym chosen by the participant at the time of the interview. No participant identifiers were included on the transcripts or demographics form. Information that could possibly link a participant to a quotation was removed during the writing of the findings. The link between the participant's name and pseudonym, consent forms, interview transcripts were stored separately in a security protected office in a locked file, at the University of Ottawa. Electronic data was encrypted and password protected, interview material was only shared between the primary investigator, thesis advisor and thesis committee.

Chapter 4: Findings

Analysis of the interviews revealed the challenges nurses confronted as they cared for patients who were at EOL. The underlying essence to this experience was one of complexity, difficulty, strain and struggle. The struggle of participants as they battled to overcome barriers to EOLC, obtain the resources they required to facilitate comfort and create a supportive environment for the patient and family. One nurse likened the attempt to negotiate EOLC in a medical environment to that of being stuck in a spider's web "because we are the ones that are really kind of caught up in the tangled web at the end, at the frontline trying to provide the care". "Battling a Tangled Web" became the overarching theme from which the seven major themes of the study were derived. The web represented the nurses' perception of the environment and the stakeholders in it (physician, family and patient) (see figure one for a diagrammatic representation of the web). The layers of the web represented the environment, the physician, and the family. At the nucleus and representing the central focus of nursing care, was the patient. The barriers to EOLC were encountered within the layers of the web. At the outer layer of the web was the environment which affected all aspects of the nurses' work and the care provided to the patient. The environment included the hospital policies and processes which dictated the routine of the unit and how interprofessional teamwork occurred. The stakeholders could act as both facilitators and as obstacles in EOLC causing the nurse to get tangled (stuck), or gain momentum to move forward (to address the goals of care, obtain resources, or provide care). Threads anchoring the web represented the facilitators, strategies and motivators nurses used to negotiate EOLC.

The seven themes of the study were: caring in complexity, caught in a tangled web, bearing witness to suffering, weaving a way to get there: struggling through the process, creating

comfort for the patient, working through the dying process with the family, and finding a way through the web (see figure two for an organizational schematic of the study's themes and subthemes). These themes represented the experience of nurses as they attempted to transition patients from acute, curative care to supportive EOLC. This journey began with the patient, whose needs were challenging and multidimensional, as they underwent a progressive decline in condition. When participants perceived that curative care goals were futile, they acted in the role of advocate with physicians and provided education to the family as a means of addressing the goals of care. It was at this point that participants described battling against the obstacles they encountered in the form of interprofessional relationships, family dynamics, and hospital processes that influenced the discussions surrounding goals of care and determined whether or not an acknowledged and planned transition to EOLC occurred. Inherent in this experience was the effect negotiating these transitions had on the personal and professional lives of participants as they strove to provide EOLC in an environment that was not always conducive to it.

4.1 Theme 1 - Caring in Complexity

Caring in complexity, represents the challenges the participants experienced in caring for patients on the medical unit. Challenges stemmed from each patient's unique medical presentation, combination of co-morbidities and response to an acute episode that typically occurred within the context of chronic illness. Caring for a patient with a medical illness was consistently identified by participants as difficult and complex. Recurring cycles of exacerbation and improvement created a complex illness trajectory, making it difficult to determine when a patient was at EOL. Caring in complexity consisted of two subthemes. The first, "*caring for the patient on a medical unit: it's complicated*", reflected the multiple comorbidities and chronic conditions present in patients who were frequently older. The second, "*recognizing the end: it's*

not a straight line” described the unpredictable, non-linear path of decline which participants often attempted to recognize in order to alert the medical team to the changing needs of the patient.

4.1.1 Caring for the Patient on a Medical Unit: it’s complicated

Patients admitted to the medical unit could present with diagnoses that were broad in range and conditions that were vast and varied. Though often elderly (65 years of age or older), adult patients could be anywhere from 18 to over 100 years of age. As Ann described

we can have elderly patients...And they are coming in, not with one illness, not with a broken hip and not with ...an acute kidney injury related to dehydration. They’re coming in with congestive heart failure with COPD, with chronic renal failure that’s in an acute phase. They may have an underlying long term, slow growing cancer along with all of that. They may have some mild dementia... And all of these things are, are in a basket, and it can be one or two of those things that exacerbate and they’re very very sick.

The medical complexity of these patients and the care they subsequently required was described as challenging by the participants, particularly as it related to difficulties experienced in achieving a tenuous balance in treating one illness while not triggering an exacerbation in another.

Elderly people are very, very fragile and you have one thing that gets out of whack then everything goes all out of whack. And more, so they’ve come in with a UTI, they’ve gotten septic, they’re completely delirious, then we’ve had to hydrate them with IV antibiotics and fluid, then they go into some CHF failure and oh my gosh they have a new COPD, whatever. And it all just accumulates and they’re really, really, really, really

sick, and it takes them a lot longer to recover than a person younger than 65, so that complicates everything. And it's a huge challenge from a nursing perspective. (Ann)

Patients could also experience atypical responses to treatment and not necessarily what could be expected based on normal adult treatment ranges, textbook, pathway or practice guidelines responses. As Anne explained, "It can be anything then, you know? Nothing makes any sense anymore! You might follow the book; you might not follow the book so...I have to take care of people on an individual basis because none of you are the same!" The unpredictable and individualized response to illness and treatment often required participants to think "outside the box" (Ann).

4.1.2 Recognizing the End: it's not a Straight Line

The hospitalisation of patients on medical units was described as being a non-linear process; unlike other specialities, in medicine "there's no straight line" (Ann). Patients, who seemed to be at EOL one moment, in the matter of hours, appeared to be on the path to recovery. For example, Anne described "and you'll get, 80% will go that way, then get 20% you have no...idea what's going on; one minute they're Cheyne Stoking, the next morning they're sitting up and eating breakfast". At times the impact of illness, coupled with the effects of therapy was too much for a patient to tolerate. Some patients came to a point where they could no longer endure the exhaustion of another round of therapy. A fluctuating course of decline was also exemplified by negative effects of therapy, a progressive deterioration from a patient's baseline, disease progression and a lack of response to therapy.

Participants stated that it was most often the nurse who was first to raise concerns with physicians when the patient's health did not improve with treatment; Kate described nurses as gatekeepers who were responsible for reporting information back to the medical team. To

facilitate communication with physicians, participants most often utilized the reporting of medical and physical findings to reflect the patient's deterioration. As Ann describes

Well usually we'll be reporting to the doctors...that the patient is weaker today, no longer eating...urinary output is low, you...can't get any more IVs on them, non-responsive, Glasgow Coma Scale is going down, the family are...becoming anxious, and...things like that.

Participants however were not only concerned with physical or medical findings, but the patient's overall response to therapy. Participants monitored the psychological effects of prolonged treatment, the patient's tolerance and ability to cope with treatment. Frequently the patient's physical exhaustion, inability to tolerate treatment and a sense of futility of care represented a turning point for participants to address treatment concerns with physicians. The desire to halt patient suffering was the primary motivator for participants to advocate for a shift in the focus of care from aggressive treatment, to supportive, EOLC. As Anne related:

It is through our reporting...to the doctors and the team that we see that treatment isn't working and we do come to the point where we've exhausted everything...it is the nurse's reporting to the physicians that we're getting to that point where we don't think that this patient's going to be able to tolerate any more treatment let alone come through it. ...The person themselves is exhausted, they can't continue to fight...so then you have to shift the care so that at least the suffering stops.

The nurse's report of deterioration became the stimulus for the physician group to approach the family for formal discussions surrounding EOL.

4.2 Theme 2 - Caught in a Tangled Web

In this theme, participants encountered barriers when attempting to advance discussions regarding the patient's plan of care. Participants were caught in the middle between the opposing expectations of families, patients and physicians. Nurses in the study experienced feeling tangled in the reality of providing care in an environment in which there was a lack of cohesiveness among stakeholders and this lack of consensus further impeded the progression towards clear goals of care. As Ann explained "Families will have their own goals and expectations. Physicians will have their own goals and expectations. And nurses are kind of stuck in the middle." Ann continued "So there's many ways that we're kind of in a tangle, trying to provide the best for the patient while still being a member of that team and going along with care as it's established." Another participant graphically expressed how nurses tried to stay patient focused. Anne stated:

You got your patient right here (Anne cups her hands together in front of her), then you got the family and everybody else (Anne opens her hands and moves them out to create a wider surrounding circle), and where's nursing? We're kind of the whole thing surrounding all of it, trying to be patient centered care. Always patient centered. Always looking out for the best interests of the patient and extended to the patient's immediate family. And sometimes we're caught in the middle between the family and medicine about, you know, between what we should be doing and what we could be doing, and what we can do.

The subthemes reflect being caught in a tangle and include: "*dealing with unclear goals of care*" which explores the physician related barriers to transitioning to EOLC as well as the impediments and repercussions when working under an undefined plan of care and "*families not*

seeing the end' which examines the obstacles which hindered the family from realizing that the patient was approaching EOL.

4.2.1 Dealing with Unclear Goals of Care

As the patient's condition changed, the need to clarify and confirm the goals of care was often required. However, the goals of care were unclear and did not reflect the changing circumstances and needs of the patient. Ongoing therapy did not appear to be accomplishing a direct purpose such as an improvement in condition, but continuing by rote and physicians were perceived as "*treating to treat*". Participants also came across barriers in the form of a perceived physician mind-set of cure at all costs. Many participants attributed this "fix it" mentality as originating from medicine's "*fundamentally different philosophy*" or view of death as failure. The propensity of physicians to want to hang on too long was associated in particular to the inexperience of residents and medical students who were thought to have yet to learn to accept death as a natural occurrence.

4.2.1.1 Treating to treat: Caring in ambiguity.

Participants found that patients admitted to hospital for acute interventions, who were not improving despite therapy, often had unclear goals of care. As Ann reflected:

So, I find that we'll have physicians directing a plan of care that's maybe not quite defined. They're still offering treatments, maybe not super aggressive treatments. But they haven't really defined, we can't treat to cure, we can't really treat to improve a situation. We're just kind of treating. We haven't really focused what the goals of care are going to be.

Additionally, caring for patients who were actively dying under a curative plan of care was described as stressful and demanding. Participants were expected to assess, monitor, report

and document an acute decline in patient condition, but the medical team did not always address the deterioration. This created ambiguity as Bob described:

I find the biggest problem with it not being so clear like that is...when the patient is...end-of-life and it seems like they're going to be dying soon but they're not yet considered like a palliative end-of-life patient and they're still getting treatment, we're still checking their vitals, that can be hard because as a nurse we might find oh today their, their pulse is super high and their blood pressure is low what are we going to do? We'll call the doctor but they don't really want to treat that thing because they're going to the end-of-life soon....so right at that transitional stage it's, it's very difficult sometimes...I think it, it can be challenging when they're not fully comfort measures on paper but we're still treating them and checking stuff, doing labs and stuff when, when we're not really responding to the results and that can be hard.

It was not always clear from the patient's health care record what the goals of care were or the purpose of the provided treatments. At times participants drew their understanding of the goals of care from informal discussions with other health care providers. Sal described how through report and conversations with other nurses that he became aware of the palliative nature of the patient's condition:

Another nurse would mention it...they realizehe doesn't realize that this person's actually palliative because it may not say palliative anywhere...sometimes...you get it through report but it doesn't actually say palliative anywhere...that's a little confusing.

Confusion regarding the goals of care also occurred from the number of health care providers rotating through the patient's care. Clear and ongoing communication between health care providers was challenging. As Ann states "The goals change from day to day like (medical)

staff changes in this hospital...it doesn't help because they all bring their own different perspectives, and different ways of looking at things and different approaches.”

4.2.1.2 Fundamentally different philosophies.

Participants perceived that conversations between nurses and physicians about EOL were difficult due to the fundamental differences in viewpoints between these two groups of professionals. Madeline voiced, “it’s hard to explain to the doctors...they don’t understand and then...you just don’t want to push the envelope because there’s a few doctors that you just know are not going to be on the same page as you.” While physicians were thought to subscribe to a primarily curative philosophy, participants were focused on a philosophy of comfort. As Madeline explained, “it’s very difficult to talk to medicine doctors about end-of-life... Because they’re medicine doctors and they’re here to save the world and they’re not necessarily here to make the patient comfortable”. Participants were concerned mainly with care from the patient experience, the patient’s response to treatment, and above all ensuring comfort by minimizing unnecessary interventions and suffering.

I’m not pushing for them to die...just to make them comfortable...making somebody comfortable is not doing blood work every six hours, not poking them like, why are we doing some of this blood work when they’re not...looking it up or they’re not following through with it. (Madeline)

While the medical battle against illness was likened to fighting a war, participants were less likely to view the shift from curative care to EOLC as a failure. The shift from life prolonging treatment to supportive EOLC did not represent a dismissal of goals, but a compassionate act which enabled the emergence of a new goal, facilitating a respectful and

dignified death which was viewed by participants as of equal importance to the care given when attempting to “save” the patient’s life.

When participants came to believe that the effects of medical therapies were futile, they questioned the continuation of invasive therapies, and advocated for an introduction of a palliative approach to care. However, physicians were perceived as wanting to “hang on too long” and continue with treatment. As Madeline expressed “somebody that’s elderly that comes in with urosepsis or something like that and they’ve had IV antibiotics and nothing’s working and they are DNR. Sometimes I think the doctors go on for too long”. As an academic teaching hospital, residents and medical students were assigned to care for patients on the medical unit as part of their four to six week training rotation. First year residents (R1) and medical students in particular were perceived by participants as having difficulties in considering EOLC as an acceptable option due to their youth and inexperience. As Ann explained:

Medical students and young residents...like R1s...they want to heal and fix everybody, they don’t look at that side of the coin. They feel that it is their responsibility to do...what they know to do to try and fix. I’m not sure if it’s maybe their life experience and their personal lives or their professional lives haven’t led them down that role of experience yet. But I find by the time they’re second year or third year residents they’ve gotten to be the junior and the senior on the team...that death is ok, that it’s ok to let patients die.

Participants attributed a resident’s learning about death and dying to occur less from formal educational preparation than from exposure to death and dying on the unit. Nurses in the study played a role in the education of junior medical residents and medical students by challenging their ordering of vital signs at EOL, or the continuing of medical therapies that were not

beneficial to the patient. As Kate explained, it's "talking to residents and newer physicians...tell me why. if we're still doing all this and you're telling ...me this is...going to happen anyway, ...Why are we putting the patient through this...?"

When physicians were perceived as not wanting to "give up", it caused a delay in initiating palliative care. The consequence of extending aggressive therapies at the expense of comfort could result in a missed opportunity to allow the patient and family to prepare for death and have the occasion to spend meaningful time together. Madeline recounts once of these instances:

Sometimes I think if they stopped and looked that, that ninety-four year old lady, if they would have made her comfort measures a little bit sooner she could have spent some time with her four sons not with this mask blowing in her face and, and all these pokes and prods and, and all these things that we did to her. I think she could have spent a couple of days with her sons and been comfortable, but medicine I think has it in their brain that they have to save the world. Sometimes I think they need to take a look, step back.

4.2.2 Families not seeing the End

Delays in addressing the goals of care at times occurred from the difficulty in connecting the physician team with the family in order for EOL discussions to take place. The routines and acuity of the unit were barriers to the physician and family coming together. Physician teams spent much of their daytime hours in meetings focused on resident/medical student teaching, review of patient "caseload" and handover process, which left them less available to the needs of the unit and family. In the evening and overnight hours, when families often came to visit, physician coverage was reduced to an on-call physician or medical student to cover the needs of

the emergency department and inpatient medical units. In other instances, physicians were unable to reach family for consent for EOLC as the patient's condition declined.

Participants felt that when the physician team did approach the family to discuss the patient's declining status, these conversations frequently revolved around ascertaining the patient/family's wishes regarding cardiopulmonary resuscitation (CPR), or code status, rather than an open discussion regarding an EOL plan of care. These code status discussions were felt to be inadequate since physicians did not present the full range of interventions involved in resuscitation or their consequences, and the limited ability to improve quantity or quality of life. As Ann explained:

I think physicians do a terrible job... I hear many physicians have... not an end-of-life discussion but a code status discussion with patients. And they'll say, well, do you want us to stick a tube down your throat and pound on your chest? Well of course not, but I don't want to die either. ... There's much more to resuscitation. We can resuscitate you with medications. Do you want me to pump you full of heart stimulating medications, fill you full of fluid until you practically drown kind of medication or fluid, or what have you, to resuscitate you? ... you might have to be on dialysis for the rest of your life. ... We can resuscitate you with BiPAP and CPAP, what a horrible way to die, with a machine blowing in your face.

Not all patients who were approaching death on the medical unit had their plan of care or resuscitation wishes addressed and documented. In some instances, the medical orders on the chart still reflected acute curative management with full resuscitation orders. Even when the medical team and family anticipated that death was near, the transition to a "comfort measures only" scenario did not always occur. In one particular case Sal, a novice nurse, felt guilty after

the cardiac arrest and sudden death of his patient, only to learn that the family had been aware and expecting the impending decline. As Sal recalled:

that was my first official death and that was very difficult...It surprised me actually...and just by the end of it... my adrenaline was going so fast...and he passed away, the blood just dropped from my face, I had to sit down...I'm thinking oh my god what did I do, what did I not do you know...and the family member relayed to me...said I brought my kids in earlier today because I knew this was coming, the family member she knew he was starting to go and they expected it any day now.

The failure to address category status in situations of predicted death resulted in a missed opportunity to provide EOLC for the patient and family and resulted in distress to the nursing team who were required to provide resuscitative interventions in the face of futility.

One of the most common barriers to EOLC was families who did not accept the patient's worsening condition. Participants could not access the tools for comfort, such as medications and consultations, when EOL was not openly acknowledged. Kate found it disheartening when denied the mandate to provide comfort care, she said:

I think we all should play a role but when you have something as important as the family not really accepting it or being talked to about it....it's just to me so hard to provide comfort care to a patient with a family who doesn't even realize that...is misguided in thinking that their family member's going to get better. That's definitely one of the hardest, and it's usually the family I find to be the most draining component of providing end-of-life care as opposed to the patient.

Participants felt they had the skills and knowledge to be able help patients and family facing EOL. Skills, such as the use of medications to facilitate comfort, knowledge of the dying

process that could be shared with patients and families, and gaining access to resources such as spiritual care. Ross described the helpless feeling he experienced in trying to communicate with patients and families who did not want to consider that death was approaching:

Well you're helpless right because ...you have the information, you try to communicate it...the patient, the family they don't want to hear it. If you try to push it, they would go to the doctors. It finally...became an end result of you're helpless, you can't help this patient. You're supposed to help them but basically you're housing them until basically they passed away.

Family dynamics could add an additional level of complexity to EOL decision making. In some cases, the family insisted on acute, curative treatment despite the patient's willingness to die, leaving the participants ethically and morally caught. Ann described one such situation:

it wasn't about her [the patient], she was willing...had already let go, and her parents refused to let go. And the medical team was guided by what the parents' wishes were to fight fight fight fight fight fight, fight to the very end and that's what they did. And eventually her heart couldn't take it and she died. And that was hard because we all knew she was dying.

Other times, family members were in conflict with each other, with some family members wanting curative care, while others wanting to shift to EOLC. Sal describes one difficult circumstance where a son made his father palliative against the wishes of another sibling who was from out of town:

I really learned a lot through that patient experience because ...the other sibling...he didn't want palliative, he wanted everything to be done and he was very upset and he was on the phone and making threats...

4.3 Theme 3 - Bearing Witness to Suffering

Participants struggled to work through a tangled web made up of many barriers which were often beyond their choice or control. Participants expressed particular difficulty related to instances where they were required to bear witness to patient suffering without being able to alleviate it. These situations occurred when the patient's condition was progressively deteriorating towards death, yet the plan of care continued to focus on curative goals. This theme was comprised of two subthemes: "*contributing to suffering: it's out of our control*" and "*an emotional and physical drain for us*".

4.3.1 Contributing to Suffering: it's out of our Control

This subtheme describes how participants found themselves as both captive witnesses and active participants in a plan of care that they deemed as harmful to the patient. Nurses observed firsthand the physical and psychological effects of ineffective treatments on the patient. It was particularly difficult for participants who viewed their role as one of helping patients and ensuring comfort to rather find themselves as contributors to the patient's ongoing discomfort. As Ross explained, "our job here is to make them comfortable, our job is for healing, it's not to turn around and keep them here and torture them right?"

While the medical team and/or the family may have agreed on an aggressive plan of care, the difficult task of carrying out these interventions (at times on an unwilling patient) often fell upon the nurse. The effects of these therapies were difficult for participants to witness. Under these circumstances, participants who normally described doing things "for" the patient now spoke of doing things "to" the patient. Anne described providing ongoing care for a woman receiving chronic mechanical ventilation who no longer wanted to be cared for:

she was resistive to care. She didn't want us to do anything for her. She'd cried and cried and cried ... we watched the whole thing deteriorate you know. I mean, and we would do everything we could to try ...to care for her but it's hard to care for somebody who doesn't want to be cared for.

Participants also used the words "we watched" to describe their role as captive observers to suffering. Participants described situations in which they watched as symptoms worsened, despite treatment, to the point of the body completely failing. The latter was in direct opposition to many participants' conceptualization of death as a natural part of a human lifecycle. In not addressing EOL issues, patients were denied the right to die in what participants viewed as respectful, dignified and comfortable circumstances. Ann recalled:

and they were still treating her aggressively when she diedand to kind of have that experience was very, very challenging. And I don't think her end of life was comfortable and dignified.very short of breath, you know, heart failure and so grossly edematous. And she was probably...still aware, she could still answer yes and no questions and participate, but quite somnolent.that kind of wore her out as well. But it was, it was really really really difficult.

4.3.2 An Emotional and Physical Drain for us

Caring for patients in their final days of life could be both an emotional and physical drain for the nurses. Participants expressed their moral responsibility as well as professional accountability to provide the best environment and care for the patient and family during the dying process. Bayia explained:

Sometimes [it] is really, really hard...I mean when you are caring for someone in medicine in general they are really, really sick but...it is a little harder when they are

palliative care because it involve the emotional stress that you know that you are caring for someone...who might not make it today and that you ...want to give your all to do a better job for that person and it is draining physically and mentally.

It was also common for the emotional atmosphere present in the patient's room to be felt by the nurse. Participants found themselves unconsciously shouldering the stress of families experiencing acute anxiety. As Bob described:

Mostly frustration comes from when the family is very stressed and they aren't coping well and I just find that stress rubs off on to me and I, I try and do everything I can like when I feel that they're stressed to keep them comfortable but yeah I think the stress comes from just them not knowing what's going on a lot of the time, the unknown and fear that their loved one's in pain and is going to die traumatically...

Helpless, frustrated, strained, and demoralized, were some of the words utilized by participants to express their emotions in situations in which they felt powerless. Participants felt powerless most often when they realized that their voices were not being heard by physicians, families and when they were constrained by hospital policies. Feelings of being "stuck" or trapped were most often expressed in situations where participants were asked to continue to provide invasive interventions (e.g. intravenous lines, venipuncture) in cases of perceived futility, which went against their moral and professional judgement. As Ann explained:

we see it a lot...we still treat aggressively and that's very demoralizing for nurses. To treat aggressively when we, through experience, or intuition, or just by knowledge of our training, we know that we're battling a no win battle. It's like the professional judgement of that has been removed and we're not allowed...to make that decision... It's a real emotional drain and strain and struggle. As a young nurse I can remember being

outraged. I'm a really pragmatic person. And...if your time is here, your time is here.

There are not always answers.

Another source of emotional stress for nurses was being required to provide resuscitation to patients who were elderly, in the end stages of their illness, and who were not expected to survive. Ann recalled the ethical issues in the case of a patient who was 92 years old and who received CPR:

she was a little 92 year old. Her power of attorney was a lawyer who was on vacation. She was just skin on bones. And they had to hydrate her, 'cause she was severely dehydrated but in the end, she ended up drowning. And when we had to do CPR on her it was like the cartoon that the fluid was just coming out of her lungs and we had to do CPR on her and that was very tragic... but the law said she was a category one, no one there to tell us otherwise and that's what we were legally obligated to do and very very distressing for me. I have huge issues with that. Really huge issues.

Similar situations also occurred as a result of hospital admission processes surrounding resuscitation status. For example, do not resuscitate (DNR) orders of patients who were admitted into hospital from long term care institutions did not automatically transfer. In order to avoid resuscitation, a category three status (no CPR) order needed to be written by the physician and a lack thereof could result in CPR being performed despite the patients' wishes.

4.4 Theme 4 - Weaving a Way to get there: Struggling through the Process

When curative care was no longer perceived by the participants as beneficial, and in some cases harmful, they sought to have the goals of care transitioned to EOLC. The transition from curative therapy to EOLC however, was a process that required time. This theme reflects the participants' struggles as they attempted to weave around relational barriers with physicians in order to unite as a team with a common goal. While participants sought a collaborative team relationship with physicians, many described not feeling accepted as part of a larger, encompassing interprofessional team. Participants described their efforts to be part of the decision-making process and to have their professional opinions heard. The following subthemes "*fighting to be part of the team*", "*working to change the goals of care*" and "*becoming a team*" outlines some of this weaving through the web in which the nurse at times was out in front overtly advocating, and at other times worked behind the scenes to facilitate the establishment of new goals of care and to mobilize resources to support the patient who was dying.

4.4.1 Fighting to be Part of the Team

Despite the existence of a formal model of interprofessional communication and collaboration at the study site, there appeared to be a lack of interprofessional team philosophy on the medical unit. Participants felt disconnected from the medical team due to infrequent contact with the physician most responsible for patients' care, and the absence of involvement of unit nurses in the medical rounds of patients.

When describing their relationship with physicians, some participants felt a lack of respect, a disinterest in their professional opinion, a lack of inclusion in decision-making or being uninformed of the plan of care. Decision-making and reporting structures within this hospital setting continued to be grounded in a traditional system wherein the medical team

continued to drive care. Although participants possessed knowledge of the patient's condition and family's wishes, participants felt their professional opinion and concerns were not always respected or welcomed by the physician team.

Participants found it an uphill struggle in trying to break through disciplinary boundaries in order to offer their professional input. Physicians could choose to disregard or discount the perspectives of nurses when it was felt not to be in line with the medical team's goals of care. In response to this professional indifference, participants such as Ann had to strongly advocate in order to be heard,

I think different [physician] staff offer different perspectives as well. You know, [some] listen to the nurses because they have a lot to offer and others, you know, they don't care. So you're still fighting a lot of prejudices and you know, fighting to be part of the team, the multidisciplinary or interdisciplinary team to be heard and what your perspective is. They'll pooh pooh you. Well, that's not our, we're not heading in that direction. That's not our goal of care. So it's important to kind of come with some authority, and some you know, confidence from 'my nursing college says I can say this'. 'It gives me the right to give you my assessment' and to advocate.

Participants discussed challenges related to communication between physicians and nurses. Participants felt disrespected and disconnected from the medical team when physicians did not communicate the content of important/critical conversations they had with patients and families about prognosis. Madeline described the effects of one such occurrence:

It's like kind of being slapped in the face because you don't really know what, how much they've said to the patient which is a big thing and what the patient's expectations are, what the doctor said, so you kind of have to go back and you have to read through the

chart and a lot of times their notes aren't really up to date so you have to sort of console the family and the patient and then go back and kind of catch yourself up and then deal with it.

Communication was essential for teamwork and was integral in establishing the goals of care. However, nurses, who possessed intimate knowledge of patient care, were often not present at planned family meetings and therefore were unable to communicate their unique professional perspective. It was often at these key meetings where the decision to move from aggressive to palliative care would be made. Barriers to participants attending these meeting included not being invited or being unable to attend because their presence was required at the bedside. Nurses were often at the frontline performing interventions and providing care for a patient, whose condition was unstable, while families and physicians were meeting in light of this acute decline. As Bob explained:

It's not usually the nurses, I don't think, no. No. We might have a little bit of conversation with a couple of family members but the nurses aren't, we're not really invited to the family meetings...or we don't participate in them. So as far as I know it's the team sitting down with the social worker usually and or maybe some other part of the team that, the multidisciplinary team who's involved with the care maybe physio or somebody else but I really don't know because the nurses don't usually participate really...we're busy looking after the other patients and our assignment so. I'd love to go to a family meeting but it just doesn't happen really ... I mean it would be good for the nurses to be in the discussion of course but it just doesn't happen.

4.4.2 Working to Change the Goals of Care

While physicians met with the patient's family for 'plan of care' discussions, participants in the meantime continued to battle for a reassessment of the 'goals of care'. Participants employed different strategies in order to have their opinions heard. "*Advocating for a plan*" described how participants overtly challenged physicians and attempted to impress upon them the need for new goals of care. In "*aligning resources: uniting with allies to come up with a plan*" participants responded to their lack of inclusion as part of the team and not feeling that their concerns were being heard by utilizing other health care professionals as leverage to push forward their case for EOLC with the medical team.

4.4.2.1 Advocating for a plan.

The acute decline in the condition of the patient and the perception of patient suffering were motivating forces behind participants continuing to advocate despite meeting ongoing resistance. As Amy stressed:

We need to have a plan; like every day, we need to have a plan. We have to review the ... goal of care so, that way, we ... know we can provide...proper care for the patient. 'Cause I know that it's hard for them [physicians] to give up. But then the patient shouldn't be suffering just because you don't want to give up.

It often took time to align physicians to a palliative plan of care. In the meantime, participants waited for a decision to be made. Decision making related to changing the goals of care often occurred very late in the process. It was only after multiple interventions (such as invasive tube insertions) and when treatment options were exhausted that the decision to palliate was made. As Anne described "we've probably already had a PEG tube in them, a Kao feed down their nose, you know, they're probably on 100% oxygen non-rebreather, you know, by the

time that we've come to the decision that they're going to be palliative care and we withdraw all that".

One of the challenges in transitioning patients to an EOL plan of care was the layers of reporting structures within the physician medical team. As part of a teaching hospital system, patients on the medical unit were assigned to the care of a junior resident or medical student who would assess the patient daily and consult with the senior resident in establishing a plan of care. While the function, specific routines and reporting structure within the medical team varied between each staff physician, ultimately the approval of the plan of care fell under the responsibility of the staff physician. Nurses were expected to report their concerns to the resident/medical student in charge of the patient's care; however, whether or not these concerns were relayed to the staff physician was left to the discretion of the residents/medical students assigned to the patient. Amy described a scenario where the medicine resident continued active, curative treatment despite the patient's steady deterioration. It was only when the staff physician came to the bedside and spoke to the patient and family that the decision to transition the patient to comfort measures was made.

He's not doing well and they're still trying so hard! ...And he's just very sick. But then [the]...medicine team, they're not giving up. So they were still trying this and that, and this and that. ... They just couldn't come up with a plan... They just can't find a balance. .. then finally the staff doctor came and then spoke with the team, spoke with the family. I think the, the patient himself says no more, this is it.But I just felt so bad. Like the patient was in a lot of pain.... Is this really necessary?

Nursing expertise, confidence and comfort in their role were necessary in order to challenge physicians and advocate for a plan of care focused on palliation. Experienced nurses

on the medical unit were more likely to question the appropriateness of the current treatment plan. Novice and part time nurses were less likely to feel comfortable doing so. Ann, an experienced nurse, described the difficulties associated with being a patient advocate:

And getting to a point where you can advocate. Because I think if you don't work full time and you're not with the same patients over and over again, you don't get the relationship or the knowledge of the situation enough that you feel confident enough to advocate for that patient. Like sometimes it's easy to go in a situation that's cut and dry, it's easy to advocate, many are not.It's taken me 30 years to get to the point where I can say that with some confidence. And I have to go back to my college standards quite often and go, yeah, it's ok, I can do this. And I do that a lot because that gives me some strength to advocate more for patients from a nursing perspective.

4.2.2.2 Aligning resources: Uniting with allies to come up with a plan.

In an effort to challenge the appropriateness of the current curative focused plan of care, participants would attempt to align themselves with other health care professionals who would act as allies in trying to force a medical decision regarding goals of care. It was a common occurrence for patients with medical conditions to require respiratory support, and therefore participants often sought the assistance of Registered Respiratory Therapists (RRT). The assistance of RRT frequently coincided with the care of patients diagnosed with end-stage COPD, end-stage heart failure, or pneumonia. As a patient's respiratory status declined, physicians often ordered non-invasive positive pressure ventilation (NIPPV; e.g. BiPAP®) as a support to breathing. NIPPV required that a mask be strapped to a patient's face, covering their mouth and nose and allowing the machine to deliver positive pressure to keep the airway open. NIPPV, however, was neither a permanent nor curative solution. The greatest risk in terms of

EOL issues was the possibility that the patient would become reliant on this therapy for survival creating an ethical dilemma; the patient could not remain indefinitely on the therapy due to their inability to eat (risk of aspiration), and likewise the patient could not survive removal of the NIPPV unit.

Participants and RRTs attempted to safeguard against the inappropriate and indefinite use of NIPPV. Ann explained:

We're very lucky to have a head RT who takes the team to task and says: how many hours are you going to try this? How many days of the week are we going to be doing this for?You know you really have to get those goals of care hammered out.

In some cases NIPPV was agreed upon as a short term trial or a temporary measure to buy time for the goals of care to be determined by the physician team. However, despite their expertise and knowledge in managing the respiratory needs of patients and use of supportive respiratory therapies, RRTs came up against the same barriers as participants when it came to influencing the patient's plan of care; the final decision fell to the physician, who could be resistant to relinquishing an aggressive plan of treatment regardless of the professional input of other health care providers.

The second group of allies identified by participants as facilitators in plan of care discussions was the Palliative Care Consult Service (PCCS). Nurses were unable to self-initiate a referral to the PCCS and had to advocate to the medicine team to consult the service on their behalf. Participants identified barriers in obtaining a consult when the medical team (as gatekeepers to the consultation process) did not feel it was time to consider an EOL scenario, or believed they could manage the patient's needs themselves. Participants however, advocated for the involvement of palliative care early in the dying process. As Kate explained:

I was an advocate for a patient that was actively dying but the team, for whatever reason, just wasn't seeing it...and I actually put the palliative care consult in...and they allowed me to do so and they co-signed ...but otherwise they wouldn't have done it at that time. They were waiting. And when palliative care came up, they [palliative care] had said to me 'why haven't we seen this person before?'

The palliative care team were seen as facilitators who could help transition the medical team towards comfort measures. In difficult situations, the palliative care team had the potential to become a unifying force bringing the physician, family and patient on board towards a common goal. The PCCS was another voice to challenge the goals of the current plan of care and were more likely to offer suggestions on how to enhance comfort as part of the ongoing treatment plan. As Ross recalled: "I can remember seeing a [palliative care] doctor one time turn around and looking at the family and...saying 'this is what we can do and this is where they're [treating team] going and what do you want to do?'...where do you want to go?" Unlike earlier descriptions of feeling disconnected from the medical team, participants describe the easy working relationship, clear goals, and effective communication they experienced when working with the PCCS.

4.4.3 Becoming a team

As a common EOL goal was negotiated, the sense of an emerging team began to be expressed in the participant interviews. At this point in the transition from curative care to EOLC, participants were more likely to use the term "team" to conceptualize nurses, physicians and families working as one, rather than nursing teams, physician teams, patients and families as separate entities. This theme highlights the positive synergy when team members no longer seemed to be working at cross purposes. Participants could now focus their knowledge and

expertise to advocate for the tools they needed and coordinate to get everything in place to promote the comfort of the patient.

Once an EOL goal of care was accepted, and most importantly, openly acknowledged by all stakeholders, the participants described how their struggle seemed to ease. As Ann related:

I think awareness that that's where you are, on this page with this particular patient. Like the goal of care. Like it's out there, it's in the open, it's been stated that this patient is at end-of-life and we're all on board and we're all going to make sure that everybody is going to help this patient get to that end-of-life with comfort and dignity and as much support as the patient and the family need. Rather than the nurse who feels like that they're the only one working toward that when everybody else is kind of still working on other things. Cause that's really what it feels like sometimesSo I think what helps is knowing that the resources are there and that we're all playing the same...game, we all have the same goals and that's to make this patient's last days as comfortable as possible.

Once the goals of care had transitioned to comfort care, the participants regarded their relationship with the physician group in a more positive light. As Bayia described "here you have many people...you have a team.....because every corner, every group of professional they like to do the best that they can to satisfy their...corner of care." The transition to EOLC allowed the participants to stop the chaotic race of trying to stem the inevitable decline in patient condition and refocus care and efforts to promote the patient's comfort. Participants assumed the role of care orchestrator, suggesting supports, consults, or services they felt could be beneficial to the patient at EOL. Participants were most likely to raise awareness of the sometimes subtle needs of the patient and coordinate discussions and communications within the health care team, patient and family to access these supports.

And...you're directing and ...orchestrating and turn around to get the patient and the family and the doctor and whoever else...and [I] say okay we're going to get this so that everybody is getting the same information so it's a team thing. (Ross)

4.5 Theme 5 - Creating Comfort for the Patient

The transition to EOLC did not necessarily mean that the struggle of participants had ceased. The environment on a medical unit influenced the comfort of the patient and could act as a barrier to the provision of comfort care. All of the study participants identified the facilitation of patient comfort as their primary goal in EOLC. Comfort was envisioned in different ways by different participants. Descriptions of comfort often were physical in nature and included pain and symptom management, the discontinuation of tests and invasive treatments/procedures as well as the routine monitoring of vital signs. The perception of good nursing care at EOL was achieved when the patient experienced no distress, no suffering and death was peaceful. The patient's experience of comfort could be affected by a number of factors which participants attempted to manipulate and control. "Creating Comfort for the Patient" follows the participants' efforts to create physical and emotional comfort for the patient while struggling within this environment. As comfort was a multidimensional experience (physical, emotional, environmental, spiritual etc.), nursing interventions employed to affect comfort were likewise multifaceted and focused on "*trying to create calm within a hectic and demanding environment*", "*bringing about physical comfort*" and "*providing emotional comfort: creating and sharing moments*" with patients.

4.5.1 Trying to Create Calm within a Hectic and Demanding Environment

The medical unit environment was often described by participants as not being conducive to EOLC. The busy nature of the medical unit meant there was constant movement of people throughout the hallways, noise from the clattering of equipment, and the sound of call bells that could persist at any time of day or night. As Sal described:

especially with the noise...even today we had...a patient yelling for four hours...and it's very disruptive to the rest of the patients and the rest of the floor... it's pretty chaotic up there for someone who's in a palliative...level of care. It can get a little wild up there.

Lights were described as “always on” and interruptions frequently occurred during the night as participants woke patients for either scheduled care or assessments. Even the physical layout of the unit, the size of the rooms, the congestion of equipment in the rooms and hallways, created a sense of chaotic clutter, a physical barrier that required moving or dodging in order for the participants to reach the patient.

Other barriers to providing EOLC included lack of time, unrelenting workloads and balancing the pressure of competing priorities of acuity, unit demands and patient needs. As Bayia explained “Medicine is challenging in every way of it. It just is hectic, demanding; there are many things to be done, it just, I don't know it's just never ending”. Participants described their sense of having to rush through their day in order to manage the multiple care needs of their patients. Participants had to balance the care of patients who were acutely ill and receiving curative treatment while trying to provide EOLC to others. However the demands of the unit were focused on acuity which left participants feeling they did not have adequate time to provide support to patients their families at EOL.

The limits of physical and human resources were also a barrier to the provision of comfort care. Nurse-patient ratios and limited staff impacted the nurse's time and ability to tend to basic nursing care. As Kate explained:

what gets in the way of good care is nursing ratios, so staff to patient, and I know it's a bigger topic out of control... [but] how can you efficiently provide the most efficient, extensive appropriate care if you don't have the time to do it?...in an ideal world you would spend your time in other areas helping that patient.

Participants attempted to shield patients who were dying and their family from the chaotic environment by consciously "*needing to slow down to provide EOLC*" and secondly by altering the physical environment to "*maintain privacy*".

4.5.1.1 Needing to slow down to provide EOLC.

Participants strove to find a way to provide care simultaneously in two opposing mindsets; the mindset of acuity and that of EOLC which required a shifting of thoughts, behaviours and goals as they moved about their work. Participants attempted to shift gears and slow down when moving from the room of a patient requiring high acuity care to a room in which a patient lay dying. Sal described the challenges in managing multiple gear shifts throughout a shift:

It's very chaotic...and it's such a change of gears when you're going from a person [in] room one who's palliative to a person in room two who's completely delirious and almost threatening to fall...into...gear three with someone in isolation and you know I mean I know you're supposed to round on everybody every sixty minutes but you know when you're having issues, safety issues with someone in room two who is about to fall... [and] I've got to call a RACE on this person or you know maybe a code...and

you're wondering how having palliative care on medicine floor unit.... is that the best place?

While the management of acuity required the nurse to be rapid and efficient with his/her activities, an EOL environment was one in which participants wanted to minimize their intrusion, noise, and stimulation. Participants were conscious of the environment, the speed of their movements, the tone of their voice and approach in care provision, all to enhance comfort. It took a conscious effort and presence of mind for participants to be able to switch gears, slow down both physically and mentally, to adopt a quiet, calming presence. As Anne explained:

we can be zipping up and down that hallway and then stop, pull yourself together, and then go into the room very quietly. That's part of your nursing...being able to switch from your high-powered energy of saving lives, to helping this one have a nice exit.

4.5.1.2 Maintaining privacy: Creating the right atmosphere.

One of the first comfort measures employed by participants when a patient was at EOL was to attempt to alter the environment to provide privacy. In a hospital setting, dying was often on display; it was difficult to ensure privacy in general as Bob explained: "I find family members and even other staff...as they're walking by, they look into rooms...and I wouldn't want people looking into my hospital room if my father was sitting there dying, so it's very public and open."

Hospital processes, bed occupancies and the need for efficiencies (minimizing "unnecessary" bed transfers) at times became barriers to obtaining a private room. According to hospital policies, patients at EOL did not get priority for a private room. The transfer of patients within the unit was discouraged from a resource allocation perspective, and private rooms were often required for isolation. For those patients who were unable to obtain a private room, participants adapted the environment in order to promote as much privacy as possible and to

reduce the number of disturbances to the patient and family. Strategies included closing the door or curtains between patients. Participants arranged the rooms to provide maximum access and comfort for the patients and their family, as Chloe described: “we’ll put comfortable chairs in the room for the family, Kleenex boxes,...make sure that they’re comfortable...we’ve even gotten cots for family members to stay overnight”. Anne used similar techniques to adapt the environment to enhance comfort, “we may position the bed differently in the room, so better access for the family. If someone wants to lie beside their loved one, we’re not going to lose our minds about it...it’s about nursing both the family and the patient at the same time”.

Families were also encouraged to transform the sterility of the hospital room by bringing in familiar objects of home. As Ann described one family’s attempts to personalize their mother’s environment. The family brought in “a comforter and their...bedside table from home. They had the stereo, provided music, all of the comforts that their mother would have had. Like her favourite puff, her light”. For participants, it was very much about making patients and their family comfortable in the room, having the family feel welcomed and creating a “home away from home” in a foreign environment.

4.5.2 Bringing About Physical Comfort

Nurses employed good basic nursing care to promote the physical comfort of their patients including repositioning, linen changes, frequent mouth care, and bathing. Participants were also conscious of the aesthetics and physical appearance of comfort, particularly when the patient was beyond a verbal/conscious state. There was a focus on the control of symptoms that could be distressing to the patient or family, the position of the patient’s body, and the appearance of restful sleep. As Ann relates

I always want to make sure that I am paying attention to what I perceive are the physical needs of the patient and what the needs are that the patient can actually communicate to me. If not, then it reverts back to what my basic nursing skills are; that they're clean, that they're dry, that their...pillow is fresh, their sheets are not wrinkled, that they're not perspiring profusely in a wet pyjama, that if there's any medications, I can provide them in a timely fashion, to keep them comfortable, I will do that as well.

In general, as much as possible, the de-medicalization of the patient's physical body and environment was attempted. The removal, for example, of intravenous infusions, nasogastric tubes and urinary catheters was seen as a step towards enhancing the physical comfort of the patient, unless the presence of the line/tube proved to be of benefit to the patient's comfort. As Anne illustrates, "We might ...keep the catheter in so that we don't have to roll them around and change them as much...take lines out that don't have to be in there... Keep the catheter in or take the catheter out, depending on what is going to be best for the patient".

Good symptom management was an important aspect of enhancing the physical comfort of the patient. Nurses closely monitored and provided interventions in order to manage symptoms that may be distressing to the patient or visually distressing to the family. As Ann suggested:

dying is a very, very strenuous process and the patients can suffer... and work very, very hard during the dying process... it ...doesn't have to be hard work, it doesn't have to be a struggle to die. It can be quite comfortable, quite dignified and medications are often the key to that.

Participants became experienced in knowing what medications they would require to enhance comfort based on the medical condition of the patient. One of the main tools that

participants requested from physicians was medications for symptom management such as analgesia. As Bob related: “I think advocating for medication is a big thing and we don’t usually have problems with that. I find with end-of-life patients if you, if you need medication, if they’re in pain, then we’re pretty good about giving it to them when we need to”. However, in some cases, participants felt that the medications ordered by the medical team were inadequate. Residents and medical students in particular were perceived as being inexperienced in the ordering or adjusting of medications for comfort. When the ordering practices of the medical team were considered insufficient, or patients presented with challenging symptoms, participants advocated for a consult to the PCCS for their expertise and assistance.

Despite participants’ efforts to provide optimal physical comfort, barriers still existed. Nurses were aware of what resources they needed to promote the comfort of the patient, however, at times hierarchical reporting structures could be a barrier. Practices, such as the requirement to cluster telephone calls to physicians overnight (e.g. one phone call made whereby nurses reported on several patients), impacted nurses’ ability to obtain timely interventions, for example, modifications to existing orders for pain control. As Amy shared, “nurses...feel a little hesitant, because there’s protocols you have to follow. Like, if it’s not urgent, don’t call, wait just for the morning. But, I think palliative...it’s a little different...your goal of care, it’s a little different”. Availability of equipment could also be a barrier. Ross described a situation where he had to order a pain infusion pump (e.g. CADD[®] pump), however, there were no pumps available and therefore his ability to provide adequate comfort at EOL was impacted. As Ross illustrated:

we’ve had a couple times where okay we have no CADD[®] pump, but we have an order, so what do we do right? So we have to go back to ...the routine, we’ll do it manually or whatever, but the patient isn’t as well controlled. That’s usually resolved in a day or two.

4.5.3 Providing Emotional Comfort: Creating and Sharing Moments

Providing comfort also included the emotional support that participants offered to their patients. Participants sought to temper the patient's anxiety by reassuring them of their presence through the use of their voice and touch to make a physical and emotional connection with the patient. Anne recalled how she used verbal and non-verbal communication to ease a patient who was dying, saying:

'Yes, the end is coming, but...you're not alone', then you start going back to 'you're not alone. Are you having' any pain? I don't want you to have any pain. You are not alone' and you start ...holding those hands. So the human touch is really something, there's a lot of power in that...

For patients who required emotional-spiritual support, participants had access to the department of Spiritual Care at any time of day or night.

Despite demanding workloads, participants described many instances in which they would make the time to go above and beyond the normal expectations of their role in order to meet the special wishes of their patients who were dying. Ross described one such scenario:

I can remember one patient who was palliative and they actually got married and it was ...organized here, we had to organize all that for her... You have other patients that they have goals...they want to go on a trip or they want to live long enough to see a grandchild get married or some other scenario so you get very diverse...you don't know what they're going to ask for. It's like a wish list and some things are feasible and sometimes we don't know; we just have to ask. So you just have to be open and try to get them what they want and sometimes you're successful, sometimes you're not.

Regardless of the busy nature of the medical unit, time constraints and unpredictable acuity, participants still found time to create and share moments with patients who were at EOL. It was about spending the time to do the little things for comfort, which meant so much to patients. Bayia described the sense of wellbeing her patient felt from her simple act of giving him a shower. Showering, an action that could normally be considered unexceptional in everyday circumstances, in this instance led to a shared moment between the patient and nurse affecting a greater emotional impact. Bayia recounted:

So I said ‘Sir, today I’m going to give you really...nice shower at whatever time you decideI promise you I will make myself available’.He calls, so I answer, and I came immediately. I gave him shower...after the shower, he said...‘I never thought just water can make you that happy. Right now I’m really feeling comfortable’.... and you just connect, like, ‘what do you have in this water?’ ‘Absolutely nothing, just water Sir’ and he was like, ‘okay, yeah’. And then he just out of the blue start crying and I cried and at that moment you feel like okay, he’s crying in front of me and I’m crying and I just, I gave him hug and I didn’t even know what to say at that moment. I just hugged him, and I cried and he cried and that was the moment that I felt oh my god, he’s really going to die.

Even the warmth derived from a cup of coffee could be the basis of providing emotional comfort and creating a sense of connection through the caring it demonstrated from nurse to patient. Bayia recalled the contentment her patient experienced from one such simple gesture:

one of the people who was passing away in her last moment with me was just her coffee, coffee and cream and she ... just opened her eyes and she said that was the best coffee ever and not even an hour and a half after that she passed away. So there is moment like

this that.... I feel like a chip in my soul, like ... little by little there are people that you come in contact with they become part of your soul. I don't know it sounds silly to say it but they take a little bit from your heart.

Participants recounted how they accompanied patients through to the end of their life's journey. Through their constant presence, participants attended to the needs of patients and supported them through the effects of their illness and sought to be present at the time of death. For many participants, it was about trying to bring the patient to a state as close to total comfort (physical, emotional, environmental) as possible, as Anne described:

I finally get that patient to the place where they're no longer in pain. They're breathing ok. They got their family around, and they're a little bit with it so that they can notice and see that things are happening around them and they can feel comfortable enough to go to sleep. And relax. That's where I want my patients to be, where they're kind of semi-aware of what's going on but they're ...really comfortable. And they're able to just enjoy that moment with no pain, with no distress. And those are, you want them to have that as long as possible.

4.6 Theme 6 - Working through the Dying Process with the Family

As the patient approached death, they were often accompanied by family who journeyed with them. While patients were consistently described as the focus of nursing care, participants describe a widening of their circle of care to incorporate the family. The nurse's relationship with the family was a key component in providing effective EOLC. The family, in their role as either a substitute decision maker (SDM) and/or as a concerned support system, was influential in the type of care that was provided to the patient. Families were instrumental in determining what treatments/interventions they viewed were necessary for comfort. Participants described

supporting the emotional and informational needs of the family, which became more immediate as the patient approached death. As Anne explained:

[that's] your palliative care setting...it's about the entire family, not just the patient. It starts with the patient ...as the patient goes away, you expand your nursing to the family and that's the way palliative care is. Your job's really over when the last family member leaves the room.

This theme explored various aspects of the nurse's role as they worked through the dying process with the family. The first step in this process began with "*building a relationship with the family*" in order to be able to effectively "*support the family*". Building a relationship often occurred as an outcome of "*spending time*" and "*earning trust*".

4.6.1 Building a Relationship with the Family

Participants recognized that families, just like the patient, required their time and presence in order to build reassurance and diminish anxiety. Participants identified that the family and individual family members had their own set of needs and expectations. Ann explained, "you have to kind of get to know the family.....everybody's experience is very different". A crucial first step in getting to know the family, to be able to effectively nurse them through the dying process, was to spend time with them.

4.6.1.1 Spending time.

On a busy medical unit, it was often difficult to find the time to spend quality moments with the patient's family. Participants expressed feeling torn between workload, managing patient acuity and maintaining a constant surveillance of other patients while simultaneously trying to be in the moment as they spoke with families. Since it was difficult to obtain a private

room for patients at EOL, the nurse was trying to provide a quiet environment for the family while monitoring the patient in the next bed who could have urgent needs. As Bob explained:

that's the challenge too! Because you need to spend that time. And on the medicine floor you have...your other patients who could be confused and they're climbing out of bed at the same time and you can see them in the corner of your eye; you want to get up and protect them but you really need to like be gently with these family members and spend some good time talking with them, but it can be hard.

Misconceptions existed that a patient at EOL required less nursing time as they were thought to be "less acute" requiring fewer interventions and only the basics of physical care. However, the time required to determine the needs of the family was often not taken into account. Kate explained:

...being there as a support person for the family which to me sounds like a heck of a lot of work. So I don't know when people say "oh good they're comfort" or "don't worry...now twenty-eight's comfort" it's like okay...Yeah, they may not be ringing their bell every two seconds but they still need us just as much and maybe more than ever to help them ...make that passage you know....it's something that I really think a lot over.

The time required to adequately assess and identify their needs could be lengthy and the process quite complex, particularly when individual family members were at different stages of acceptance of the impending death. Even within one family, the degree of coping achieved by individual members could be vastly different. Sal described the level of difficulty involved in providing care to a family with complex dynamics:

there's so many variables in that room at any given moment between the patient and the family members. I mean...there's four people...each of them is at a different stage; one's

angry, one's grieving and to be able to be expected to walk into that room and juggle all that is, is a lot.

While in some cases, the time required to spend with families could be extensive, in most instances, just finding small moments was considered valuable and significant. As Kate described, "but maybe I take ten minutes of that hour to talk to the family member or get them a glass of water you know if the patient's sleeping". Often conversations with families involved simple exchanges and showing concern such as just sitting down and inviting conversation, and listening to what the family needs. Bob said:

I think the best way to reassure someone, which isn't always possible, but it's just like really spending time with them and like sitting down and just talking like. I don't really have like a specific thing that I go and say to every family member who's distressed and with their dying person but it's just kind of like you really have to spend time and just sit and see what their needs are and then just go from there.

4.6.1.2 Earning trust.

One of the challenges participants faced in building a trusting relationship with family members was related to the nature of shift work and the number of nurses rotating through a patient assignment. Families were often exposed to an ever-changing nursing staff as assignments changed from day to day and could be uncertain of the type of care their loved one would receive. Amy explained, "the main concern from the family is they're not sure if the patient is comfortable enough. And ...they're not sure if the patient is getting good care. 'Cause nurses change all the time and they are trying to do the consistency, but it doesn't happen all the time".

Gaining the family's trust could take time and required constant communication and actions that followed through. For example, Ross described how he conveyed to family what to expect during the shift, and then importantly, followed through on his intentions to gradually gain a family's trust:

to be able to ...communicate to families, to patients and say...these are the stages, this is what's going to happen right? They may not be happy with the information at the moment but I think if I tell you today...this is what's going to happen today and they see that it does happen and the next day you come in and you say this is what's going to happen and you do that on a consistent basis and if we're all consistent doing the same thing then they get confidence in that what we say is real.

Participants felt that families evaluated the quality of nursing care based on the patient's physical appearance of comfort and if pain and symptoms were well managed. Instances wherein family members lost trust in nursing care were commonly associated with the issue of pain control, specifically insufficient pain management. Regaining a family's trust could be difficult and often came down to the participant's ability to convey a sense of caring. Caring behaviours began with the nurse's attitudes, behaviours, approach, and extended through to spending time with the family and following through on actions. As Amy stated:

first it's your attitude. Like the way you are approaching...the patient, also the family. ...the tone you talk....how you treat the patient and the family. Mostly...if you do care, they will notice. So ...at the end...the family really appreciated what the ...nurse did for them.

Once the foundation of a strong, trusting relationship was developed, the next step, nursing support of the family was facilitated.

4.6.2 Supporting the Family

Participants played a central part in how families experienced the EOL process and utilized a number of supportive strategies in order to meet the varied needs of families. Participants used education, reassurance and their presence to prepare, accompany and support the family in their journey through the unknown. Supporting the family occurred in many forms including “*preparing the family*” for what to expect as the patient approached death including addressing misconceptions, “*bringing the family into the care*” to the degree they wished to be involved, and “*making things alright for the family*” through emotional support, particularly in situations when things did not proceed as expected.

4.6.2.1 Preparing the family.

One of the primary functions of nurses providing EOLC was to act as a guide to the family as they worked through the dying process. Those circumstances in which the participant had a pre-established relationship with the patient and family maximized their ability to prepare the family for what lay ahead. If there was consistency in the nursing assignment, it fostered rapport with the family. Chloe described a positive experience in which she developed a connection with a family and prepared and accompanied them through several stages of the dying process:

I had a good relationship with the patient and then she was unresponsive but then the, the relationship with the family kind of took over and....it was just a really good experience because...everything went really smooth because I knew the patient and then I knew the family and I was able to kind of prepare them...

Participants also had a role in teaching and educating families about EOLC. In educating and preparing the patient and family, the nurse not only taught the family about the patient’s

EOL trajectory, but also set a foundation for the family's knowledge and future impressions of death as well. Anne stated:

I always think...I'm doing the ultimate good, for the patient, and if I can get that patient to the end of his journey successfully then I do right by the family as well. And I hope that I never left them with anything that scares...them and also it's a teaching time too. So you take the opportunity as well to teach the family about death....we will all have this opportunity. And most times in your life you're going to experience not just one death.... so at least I hope that you've learned something through this process that you can apply to the next process.

As a result of a lack of exposure to EOL, family members often did not know what to expect as death approached. Much of the education for the family centered on the physiologic changes the patient may exhibit as they approached death, changes which could often be disturbing to families when not anticipated. Nurses in the study used their assessment skills and knowledge of the dying process as cues of knowing what to teach at which moment to families. Ann describes how her knowledge of EOL helped her to prepare the family, her role included

to watch for the changes, especially if family is...at the bedside. I often can help families as we get closer to death and...tell families what to expect.... families are very curious they kind of want to know everything that's going on, and in a supportive way I think it's important that we as nurses be aware of the EOL process so that we can share that with the families and...walk them through that.

Educating the family was also a source of comfort for them. Chloe states, it is about "basically reassuring them (family) and helping them through the process. I sometimes give them (a)...little booklet". Many participants cited the use of pamphlets and written education materials

as an approach to educate and support the family. These resources were used as tools to open up difficult conversations and offer an opportunity to answer questions.

A general lack of knowledge of, or exposure to, the dying process often allowed families to form misconceptions and unrealistic expectations of what to expect as their loved one approached death. Without other points of reference, misconceptions sometimes occurred from misinformation found in public media or the belief that once the decision to actively palliate the patient occurred, death would ensue immediately.

Misconceptions occurred from the difficulties families experienced after the transition to EOLC. Family members, who were accustomed to witnessing a flurry of acute care interventions, could misinterpret the withdrawal of these interventions as an absence or lack of care. As Anne explained:

by the time that we've come to the ...decision that they're going to be palliative care and we withdraw all that. And sometimes the family goes "what the hell!" you know; it looks like, "oh well.... That's it. We're done". And we just turned everything off.... but I have to...tell them....all this stuff we're doing right now, it's not helping him. So, we can leave it all up there if you want, but it isn't helping him, and doesn't he look uncomfortable? ...would you like to have that [nasogastric tube] stuck out of your nose here like that, when it's not doing you any good? No, let's get rid of it....you make your patient look as comfortable, and as good as possible. And that is for the patient and for the family. Because....somebody who has tubes coming out of themit's scary to look at, and we don't equate that with comfortable.

With the act of dying occurring in a hospital setting, participants described situations in which family members wished to continue with monitoring such as cardiac monitoring and the

taking of vital signs. Participants explained to the family how these technologies could impair the comfort of the patient, did not provide information that was essential to EOLC, and how nursing assessments of comfort could be performed without it. One of the more emotional and difficult issues to address at EOL was whether the patient should eat. Anne explained, “not eating is a big one. ...a lot of family members feel that if my ...loved one is still eating, they’re going to be ok, sometimes to the detriment of the patient”. When there was a difference of perception between nurses and the family, participants described needing to understand the concerns of the family and continue to involve and educate them.

Participants expressed feelings of strain and frustration when family held misconceptions created a barrier to their care of the patient. Sometimes misunderstandings occurred around the use of medications, in particular opioid and their side effects such as sedation. Kate explained the strain of witnessing her patient’s discomfort, yet not being allowed to use the tools she knew could manage the patient’s pain:

it’s unfortunate because it is the patient often who ends up suffering because of it; like [not] being allowed to give the patient medication because it makes him or her sleepy.

The family member at the bed fighting you...It’s like that role strain of trying to do your job, but you’re not going to fight with somebody, you know? And the miseducation around what comfort care is and it’s okay for the patient to be sleepy, so to speak, as opposed to awake and in a lot of pain.

4.6.2.2 Bringing the family into the care.

Bringing the family into the care imparted a sense of belonging and an active, meaningful participation in the patient’s EOL journey. In some cases, families needed to be invited into the care, as Kate explained, I “always try to involve the family because I think that sometimes

they're just scared or misinformed or misguided and confused and so by having them be a part of the process and help them kind of co-create meaning of what their experience is in that". For Amy it was about getting the "family involved, so that they don't feel lonely...at the end of their journey."

The degree to which family members wished to participate in providing direct care of their loved one was individual in nature. Some family members needed to know it was alright to participate in giving care and wanted to learn how they could contribute at the bedside. Participants would teach and model to family members the ways in which they could either provide physical care, such as mouth care, or just be present with the patient by encouraging the family to touch or talk to their loved one.

Often providing care was a collaborative effort between participants and the family. Some families were naturally inclined to participate in bedside care and were as much of a support to participants as the participants were to family. Ann recalled one particular family who shared their intimate knowledge of their mother's preferences to help guide nurses in providing individualized comfort care to a level that they would otherwise have been unable to achieve:

They [the family] knew what she liked. They knew what side was her favourite side, so when we positioned her, we didn't keep her on her other side as long. So it's getting to know those things if we have that luxury of having a supportive family to say "Well she didn't, she never liked sleeping on her left side. So when you have her on her left side, don't keep her there for very long, just, you know, she would prefer to be on her right side". So those parts are...very helpful.

4.6.2.3 Making things alright for the family.

Participants described feeling a sense of responsibility for orchestrating the event of dying for the family. Anne in particular describes the nurse's capacity of imprinting a lasting memory on families, many of whom were experiencing the death of a loved one for the first time. Death was viewed as a major event in a patient's and family's life.

You only get to do this once. You don't get to say, "oh well, it didn't work the first time; let's try that again." No. No. It's a one-time deal and it's an experience that everyone is going to remember. ... we get to see that a lot...this is maybe the only encounter they have with death in their lifetime; so we have to be mindful of that as well. Things that we take for granted can...scare...somebody, you know. So there's a lot of things going on in our...nursing minds while we're caring for that patient that is in the process of dying.

(Anne)

One of the most demanding and persistent challenges participants faced was meeting the emotional needs of the family. The need to continually check in with families and provide frequent reassurance was cited by many participants as one of the most difficult aspects of their job. It was often easier to control the symptoms of the patient, than manage the emotional needs of the family. Finding the time on a busy medical unit to be continually available to meet the requests of the family was difficult. For those families experiencing EOLC for the first time, the amount of support that they required in some cases was intensive. Bob described one of these instances:

this man was dying and he wasn't confused, he was, he was alert and still able to speak at the start of my shift and later on that night he died. And it just sticks in my head always and I think of end-of-life care with this, this guy because the family was massive, there

was probably about more than 10, probably 15 people in the room or standing out in the hallway while this guy was passing away...the main person that was working with him was his daughter who was pretty young...so she was very anxious, everything, like if he moved funny or coughed she would, and this was the thing too, the patient was out at the very farthest room from the nursing station. So she would come running down the hallway every time something changed for him and would want me to come and see. So that was hard, very anxious large family and the man, he was very, he was happy, I mean he looked, he was smiling, he was comfortable so that was good but it was providing reassurance again with the family.

Families could easily become overwhelmed by information and the reality of their loved one dying. In those instances where families became overcome by emotion, often it was the participant who was first there to provide emotional support. Kate shared:

A lot of emotion I think. You know, usually family members will have it together, just from my experience, when they're talking to a physician or the team and then it's good to have the nurse there, have as a support or a social worker because they look like they're listening.... they look like they get it, they look like they understand.... cause the doctor's there and they want to listen....and then the minute they leave....it's like the flood gates and "what am I going to do" and "what does this mean"....from my experience it's always been a very emotional thing and how could it not be. I think that's where the psychosocial support is so valuable....even though they may have just heard the same things...to answer the same questions that they're asked again. And if they need the physician to come back again...advocate for that.

The nurse provided a window of opportunity for communication to take place. In all the supportive interactions with family, time was required to connect with family, assess and meet their needs, and support them in this journey with their loved one.

4.7 Theme 7 - Finding a Way through the Web

Providing EOLC within the context of an acute medical environment was challenging for the participants. However, throughout this process, the one constant professional and emotional support participants identified was the availability and reliance on their nursing colleagues. This theme focused on the unique bond experienced by the participants as they pulled together with other nurses, as a team, to both learn from and support each other as they worked their way through the web. Regardless of their years of experience, participants described how they relied on each other's expertise to navigate the medical unit environment, the interprofessional conflicts, the emotions and uncertainties sometimes felt in providing EOLC. "*Finding a Way through the Web*" consisted of three subthemes: "*learning as a novice*" which explored how novice participants learn to provide EOLC; "*coworkers working together: the intraprofessional team*" revealed the support and resources nurses gave each other as well as personal and professional coping strategies. "*Balancing it all out: it's a privilege*" exposed why participants continued to battle against the barriers to EOLC on a medical unit; they felt it as a privilege to be present and care for patients and families as they faced EOL.

4.7.1 Learning as a Novice

In this study, novice nurses as discussed by the participants, referred to recent graduates with less than a year experience, many of whom were in their early twenties, and with limited personal or professional experience in caring for patients at EOL. Novice participants were learning how to communicate with physicians, prioritize care, and manage the needs of patients

with unpredictable acuity while also learning to provide EOLC. “Learning as a novice” described the path of novice participants as they attempted to build their confidence, competence and comfort in providing care to patients who were dying. The first subtheme “*learning through experience*” described how learning for the majority of novice participants came from experiencing EOLC in practice while the second subtheme, “*learning through mentorship*”, described the importance of experienced nurses on the unit who would act as mentors or role models to novice nurses.

4.7.1.1 Learning through experience.

Novice participants were expected to be able to support the needs of families while learning to navigate the web of EOLC. Managing the broad spectrum of emotions expressed by patients and families as they came to terms with a terminal prognosis was difficult. As Bob related, “I’m not very experienced, I only have two years and for me like dealing with end-of-life stuff is difficult”. Being able to understand and cope with the many emotions related to EOLC could be daunting for these new nurses, as Bob continues, “it can be difficult especially because I don’t really know how to handle the feelings I feel...sometimes...because I don’t have much personal experience outside of work with end-of-life”.

Novice participants described feeling uncomfortable in communicating with the family in EOL situations. One of the greater anxieties was the fear of saying or doing the wrong thing. Novice participants were more likely to believe that there was “a right” thing to say to families.

Recognizing, assessing, and managing the physiologic comfort needs of a patient who was dying was also challenging for novices in the study. Difficulties arose when participants tried to interpret the appropriate use of interventions commonly used within a curative care experience in an EOL context. For example, the indications and parameters for administering

and monitoring oxygen in curative situations was considered clear, however, novice participants were uncertain of their role in managing oxygen as part of EOLC. Bob related:

that's the challenge I had...and specifically to this one guy; it was when I was new so I didn't have much experience but he was on pretty high flow oxygen and I, it was just hard for me cause I, I didn't know if we should keep the oxygen, should we turn the oxygen, should I even check his sats and see? Like I don't even want to know! And so it was kind of a lot of unknown because I was new...at the same time as trying to deal with like 15 people watching over my shoulder, down at the very end of the hallway. It was kind of a big learning experience for me and I definitely took a lot from that, how to behave and act in front of family members who don't know what's going on.

The lack of clarity of what were appropriate medical interventions and monitoring in EOLC stemmed partly from confusion of the terms being used in the clinical environment. Distinctions between EOL, palliative, alternate level of care, comfort care, were not always defined and medical interventions, such as vital signs, could be ordered in any of these circumstances, Sal explained:

I mean at first I probably didn't even realize it was end-of-life, palliative, it was just alternate level of care, whatever that's supposed to mean. I think I looked it up in my textbook recently but it's just so vague because sometimes there is vital signs and sometimes there's not vital signs...it's just a little blurry.

While there were a number of ways participants could become more knowledgeable about EOL, such as through formal training, courses, in-servicing and personal reading, most participants identified that EOLC was something that could not be taught fully in a classroom or read in a book, but needed to be experienced. Many participants describe being "thrown in" or

having to “hit the floor running” when first experiencing EOLC as a newly graduated nurse. While often stressful, learning occurred most meaningfully at the bedside when influenced by the context, environment, stresses and individual nuances of the practice setting. It was through an increased exposure to situations of death and dying that novice participants described feeling more comfortable and skilled in providing care for the dying. Bob contrasted limitations he felt in trying to directly apply the information he read and experienced as a student, to the greater understanding of EOLC he felt when knowledge was gleaned from direct experience as a practicing nurse:

trying to teach people what the [dying] process is and the first few times...I had to deal with it myself, it was hard, because I didn't even really know. So I'm like trying to explain what's going to happen based on maybe some experiences I've seen as a student nurse or what I've read about, but really it's-it's so different every time, ...but I've been working two years now so ...with a little bit of experience..... I've seen it a little bit more and just from observing over time I think I'm more comfortable with the process and identifying the stages of dying and then I can sort of pass that information on to the family.

4.7.1.2 Learning through mentorship.

The presence and input of experienced nurse colleagues, who acted as mentors, was an essential aspect in the development of knowledge and skills in EOLC for participants, especially as novices. Experienced nurses, including managers and educators acted as important sources of information or as sounding boards for developing strategies to assist in EOLC. Amy recalled the significance of the presence of her colleagues and mentor in learning, “I talk to other nurses to

just get some more ideas. Like what can I do better for the palliative patients? Especially when I was the new grad I learned a lot from my nurse [mentor]”.

Learning how to provide emotional support to the family in EOL situations was particularly challenging. Novice participants looked to experienced nurses as role models for learning these communication and supportive skills. Experienced participants valued their role as mentors and role models. Anne described her desire to ‘pay her experience forward’ to the next generation of nurses:

You have got to look how many years I’ve been doing this. I didn’t get this way overnight. But you are also setting example for your younger nurses...if they have a death and dying person, and they need some advice, I’m ready and willing to help them through that.

Senior nurses were there for novice nurses to lean on and gain support when they were unclear what they should do. Sal recalled a case when he drew on the support of nurses when caring for a patient who was dying and family members were in conflict between pursuing curative care and EOLC.

I just looked to the senior nurses like okay, so am I doing vital signs or not? And they said no, you’re not doing them. He’s, they’ve been discontinued for now. So I was comfortable with that. I sort of leaned on them very much so.

The presence of experienced nurses on the unit at every shift also provided a sense of security for novice nurses. Ross explained the supportive role experienced nurses played in the unit structure as clinical experts:

Well luckily there’s a few nurses that have stayed in medicine...it’s like they’re going to stay there until they retire.having those nurses spread out throughout the different

shifts, everybody sort of goes...towards them for their information. And one of the things that we do...because it's a teaching area, because you're...moving new people in through the system.

4.7.2 Coworkers Working Together: the Intraprofessional Team

Novice and experienced participants alike identified their nursing colleagues as an important support in being able to provide EOLC. In an area where patient acuity was unpredictable, and the movement of patients, families, and equipment through the unit lent a constant chaotic backdrop to care, teamwork between nurses was imperative. Assistance came in the form of an extra pair of hands, information, advice or even the assigning of patients, and participants frequently described pulling together to help each other.

Working together was especially important during crises, for example, when a participant felt overwhelmed, or a patient was facing a life threatening crisis, they described automatically coming together as a nursing team. Nurses pulled together, delegated to one another, and made efforts to stretch themselves out so that all patient needs were met; both acute care needs and the EOLC needs of patients and families. Ross described:

when there's a problem, there's a crisis, no matter what's happening on the unit everybody pulls together and everybody has their strengths and everybody sort of falls in there without having to be told. There's those people that were running in to be at the patient and do all that crazy stuff that goes on..... There's other people that are more supportive that turn around will be on the floor to sort of pick up the patients because you have two nurses that are now at the bedside and that seems to happen on whatever shift we're on...I've seen that happen more and more times.

The nurses interviewed described experiences where they were unable to provide the level of EOLC they desired. A peaceful, comfortable death was not always possible. In working through the barriers to providing EOLC, participants often needed to vent with colleagues who understood what it was like to provide nursing care within the context of this environment. Participants identified the importance of being able to talk, debrief, or decompress with their nursing coworkers, after experiencing a particularly emotional or difficult EOL situation, or when death occurred under less than ideal circumstances. Ann explained the importance of the presence of her nurse colleagues, “I like to be able to decompress with my coworkers. I think our conference room sometimes gets a bit out of control and whatnot. But I think that’s very important, where we can have a discussion; oh my god, that was really horrible”. Being able to debrief with one another allowed participants the opportunity to process their emotions and provide reassurance when they were feeling particularly vulnerable. Sal described the emotional support he received after debriefing with colleagues after his first traumatic death on the unit:

I spoke to another fellow nurse and she just sort of debriefed me a little bit there and you know I went through what I was thinking, I was feeling about it and she was like no, you did everything you were supposed to do...don’t worry about it. So that was nice to be reassured a little bit cause once again it was my first time I thought, you know....very nerve wracking yeah, that was a real tough one. It was a tough scenario.

When encountering stressful EOL situations, participants described using a variety of personal and professional strategies to help them cope. For example, when incidents occurred that nurses felt were out of their control, highly emotional, upsetting, unexpected, or considered futile, participants sometimes attempted to personally detach from the situation and turned on a professional “autopilot” to help them be able to act in the moment. The use of professional

detachment, however, did not necessarily protect the participant from the emotional impact of the traumatic situation. The ‘professional side’ of the participant coped in appearance by working through the expected interventions and actions associated with their role, while the participant as person did not. Ann recounted a personally unsettling event that occurred when a patient died unexpectedly on the unit only to have the daughter walk in to find her mother’s body already enshrouded:

she had died completely unexpectedly; it was just one of those crazy, crazy things, and then we had to deal with the supportive care for... the daughter afterwards and yet the bagging happened and I was like totally frazzled. But I completely detached myself and was very professional and apologized to the daughter and, you know, gave my condolences. But even after I went home that night, I still felt knots and felt sick to my stomach, thinking that should not have happened. That was really awful.

Some participants were unable to leave the stresses of EOLC at work and found themselves bringing home pent up emotions. In some instances, participants internalized their stress and manifested coping through negative forms of self-comfort, as Ann explained “I know that when I go home, I’m a food addict. It’s my only addiction I have in life is food. And...I eat my stress.” For other participants, catharsis was found in being able to decompress with family and release their emotions through tears, as Bayia explained:

Sometimes you go home, you take a long shower and cry a little bit and then you call your family and just talk to them and yeah. You take it home, for sure you take it home, but yeah for me a long shower and a little cry will help me.

The act of showering and the cleansing obtained through water was used by more than one participant as a means of physically and symbolically washing away the day’s tension and

obtaining a release from emotions. Kate described her personal routine for decompressing when she arrived home:

then on my coming down time I have a whole process... I'll be professional ... and do my charting and finish up and pass on the report but when I go home, my husband knows better than to talk to me for the first forty-five minutes.....like I really do need to come down. You know you get your shower, you scrub off the day's hospital dirt and, and I just come down and I think and I reflect and I'm probably going over everything I did during the day and then a big part of it for me in that whole coming down process is practicing a lot of gratitude for what I have.

The comfort of talking to one's spouse was also a support that some participants turned to in order to relieve the stresses associated with providing EOLC.

4.7.3 Balancing It All Out: It's a Privilege

While providing EOLC in the context of an acute medical environment could be considered challenging and fraught with barriers, participants nonetheless continued to work hard to overcome and navigate through and around those obstacles with the goal of providing the best possible EOLC. This subtheme discussed the aspects of nursing practice which encouraged participants to remain engaged and drawn to EOLC; knowing they had done their best, creating an emotional connection with patients, and believing that it was a privilege to be allowed to share in and have an impact on the last intimate moments of a patient's journey from life.

All participants had the desire to do their best as nurses despite the challenges and frustrations. As Anne explained: "It comes down to we do the best that we can with what we have. It's our compassion and our empathy that drive us to care for our really sick patients until they die". For Anne, nursing was more than a job, she said:

It's a vocation, I can't go away. Well I often say that....if you think I'm here for the paycheck, you've got another thing coming...I'm here because I actually really care, ok! You know, they pay me enough, and I don't want any more money, I just would like some more help!

A sense of nursing as a helping profession that continued to care through adversity also provided Kate with the motivation to continue to fight against the barriers to EOLC, as she explained

I try to reframe it...that yes this is my job, it's my job and I don't think it's your typical everyday job...but it's more than a job, it's my profession right. I am a nurse so it's part of me. No matter what other role I go into in my life I will always be a nurse and I think...a big part of being a nurse is being there from start to finish...for better or for worse, like a marriage right, of a lifespan... it's my profession and I'm going to do the best I can to just help these individuals.

Participants cared for patients and their family in the same way they one day wished to be cared for. As Bayia stated: "If I was in that bed I would like to be treated the way I treat my patient if that was me". Participants sought to do a good job which left them with a clear conscience. Doing a good job however, was not viewed in a curative sense. The fact that the patient at EOL did not survive did not mean that the team had failed or that the participant did not do a good job. EOLC was viewed as rewarding. Providing the patient with the means of a peaceful death was the measurement of a successful outcome to the participant's care efforts.

Anne explained:

Palliative care, they're providing probably the greatest gift. One of the greater gifts in life; a peaceful, calming death. Death is mystical ok. So they're right there in all that mystery and it means something different for everybody.So for us, we have to be able

to look at that was an achievement. We reached our goal of care. And we adapted as we went along, to personalize our care for our patient, because every plan of care needs to be personalized, geared toward the patient's goals and what the patient's able to do. And so you have to walk away from that knowing that you did the best that you can. In nursing... you have to look at what you're doing...for the moment and take away as many positives that you...can.

While some participants believed that emotional detachment was necessary to provide professional nursing care, other participants such as Bayia could not close themselves off from the possibility of connecting with patients or compartmentalize their feelings. When asked how she protects herself from experiencing what she called "chips" in her soul from the loss of patients she connected with, Bayia responded:

You cannot! That thing you cannot, that, there is no way because when, there are people that just have passport to your heart, there is no way you can say I'm going to just put this here. No. For me I would not. Like today I connected with somebody, a beautiful human being...it's just the way it is...that is part of who you are as a human being.

Emotional connections occurred not only with patients, but with families as well.

Participants described being particularly touched when present as a witness to EOL discussions

As Chloe recalled one such discussion:

They pull at the heart strings. I'm not going to lie, I've walked out in tears at some point in time and you do feel quite a bond with the patient and the families....I don't find it that it's difficult, it is emotional but it's, it's very rewarding also to, to be part of that.

Participants described a unique connection that occurred with patients who had long length of stays on the medical unit; under some circumstances, admissions lasted as long as two

years. Patients with prolonged stays in many instances became a part of the unit, its routine, and in some cases, were even viewed by participants as a friend or family member. When these patients died on the unit, the emotional impact of the death on nurses as individuals and as a nursing team could be devastating. Participants described how the sense of loss lasted after the patient had left the unit and affected the emotional atmosphere. Anne recalled:

when you're...looking at someone...like our vents that died. We did have a lot of support because they knew that we were going to feel like that. It was like a family member that was dying. And, and these weren't sudden deaths. These were planned procedures. Ok. Like we knew that on this date, this was going to be the day [the patient would be]....taken off the vent and they anticipate this many hours for it to happen.....Some people....came in that day, some people didn't....people who wanted to be there to be with...our patient when...he died were there, and those who couldn't do it, were not. Same thing with funerals,....some of us went to the funerals for our patients, and some of us didn't. But we don't go to funerals for every patient...but it's those long term ones- they are the one that take their toll.

After the death of a patient on the unit, participants described the sense of having “to move on” and continue with the work routine of the unit; provide care for the patient who had died, send them to the morgue, clean the bed and wait for the next admission to arrive.

Despite the often difficult and emotional nature of EOL work, many nurses did not try to avoid caring for the patients who were dying on the medical unit, but rather enjoyed and felt rewarded by process. As Chloe explained: “I really enjoy looking after palliative patients, I really do. I mean, I've had so many good experiences that it's, it's not something I dread like it's, it's hard work and it's emotional but it's very rewarding”.

Participants found their role particularly gratifying when they were successful in bringing about comfort for patients and supporting the family. Typically there was not just one aspect that drew participants to EOLC, but rather the whole experience was seen as personally and professionally fulfilling. As Madeline stated: “when I’m taking care of somebody at the end-of-life, I like making them comfortable. I like seeing them at peace, I like taking care of the family; I like the whole...thing”. Participants expressed their sense of privilege in being able to accompanying the patient and their family during this private time. As Kate expressed:

we have a very privileged position to help take care of people in those moments... it’s something that will carve out and affect you. By talking about it, it helps me kind of process it but it’s also a gift in a sense as I called it a privilege because it makes me so much more happy and you know, grateful for what I have and the realization that health is also a privilege you know to have good health.

The follow up interview with participants

A second interview with eight of the 10 participants followed the completion of the analysis. Participants were asked to review a five page summary of the study themes and findings to allow for deeper interpretations and evaluate the appropriateness of the themes (van Manen, 1990). These interviews were audio-recorded, transcribed and verified for accuracy by the researcher. The following were comments made by participants in response to the researcher’s question “Do these findings reflect your experience of caring for patients at EOL? ”: *“Goosebumps good. Yeah, it faces all of our challenges. Yeah, especially the deciding, the teams, that’s the biggest thing that, you know, once we can get them on board with realizing they have nothing more to do, but to provide us with the tools to do the comfort thing”* (Ann); *“It’s good....It’s got a good flow to it. And I like the way that it concludes, about it being a-it is a*

privilege. And the privilege of being there when someone leaves this world, that's-that's something else that we don't take lightly either. No, I like-it's good. It's good" (Anne); *"I definitely expected a lot of this and I think it's outlined really nicely and it hit on all the big topics, like, especially for me the section about being a novice nurse. I can definitely see myself saying some of those things for sure. Ah, and then all the talk about families too, I think, that's a big thing in practice, and it's reflected well in what you have here for sure"* (Bob); *"It's like me. I feel like I'm reading my life. Like, it's exactly me. It's how I feel. Yeah, it's really good"* (Chloe). None of the participants expressed disagreement with the themes or findings provided in the summary. Participants expressed great interest in the summary and voiced that the findings reflected their experience.

Chapter 5: Discussion and Implications for Practice, Education, and Research

5.1 Introduction

This chapter discusses the findings of the study as well as implications for nursing practice, education and research. The discussion and implications are supported where possible by current literature. Suggestions for future research are provided. This chapter concludes with the limitations of the study.

5.2 The Complexity of Caring for Patients at EOL on Medical Units: The Tangled Web

The findings of this study follow the nurses' experience in trying to create a supportive environment for patients who were dying and their families. Nurses viewed their role in providing EOLC as important. Participants wanted to ensure the patients' comfort and maintain their dignity through the dying process. These nurses also sought to prepare and support families so that they could spend meaningful time with their loved one as death approached. However, the findings of this study revealed that trying to provide these measures was challenging within the active treatment approach of the medical unit. Unlike formal palliative care settings, patients typically were not admitted to medical units for EOLC, but rather patients, their families and health care professionals (HCPs) had to go through a process of transition in which the goals of care changed from curative to comfort (Clarke & Ross, 2005; Thompson et al. 2006a, 2006b). This process of transition often involved negotiating relationships with physicians and families, accessing resources, and required advocacy before a decision to pursue EOLC was agreed upon. This process of transition from curative care goals to comfort care had the capacity to generate conflict among HCPs, and between families and the health care team. Participants described the experience of providing EOLC to patients/families as weaving through a tangled web. The

tangles in the web represented the environment of care, goals of care, interprofessional relationships and the family.

5.3 Weaving through the Challenges of the Environment of Care

One of the major factors which contributed to the nurse weaving through a tangled web was the context of care related to the acute medical environment. The medical unit was physically and organizationally geared towards the provision of curative care. Acuity affected how nurses prioritized their care, the interventions they needed to accomplish, and the time they had available to interact with colleagues, HCPs, patients and families. The physical environment and atmosphere of the unit was described as chaotic, noisy, and in perpetual motion. Hawker et al.'s (2006) study of family members' perception of EOLC in a community hospital found that the noise and busyness of the hospital environment, such as the sounds made by staff, call bells and technology (television), interfered with the creation of a quiet and peaceful atmosphere for dying.

Organizational factors such as hospital structures, routines, resources, processes (formal and informal) and policies also affected the environment which affected care. Participants identified limited resources (staff/time/equipment), situations of demanding workload, limited ability to influence decision-making, as well as interpersonal conflict. They desired more organizational support in order to be able to provide EOLC. In a study by Pincombe et al. (2003), organizational factors originating from the culture of the unit/hospital, also influenced the type and duration of EOL nursing care on the medical units. The authors found that a significant proportion of nursing time was focused on routine tasks and maintaining technologies (equipment) which created "tension" when there were competing demands that "were at odds with the needs of the dying patient and the family" (p. 82). Organizational factors commonly

associated with work stress have included heavy workloads (Adams & Bond, 2000; Foxall, Zimmerman, Standley & Captain, 1990; McVicar, 2003), limited resources such as staff (Chang, Hancock, Johnson, Daly & Jackson, 2005; Chang et al., 2006; Foxall et al.), situations of “high demands and low control” (Trybou et al., 2014, p. 293), and conflict/lack of supportive relationships (McVicar).

In addition to these barriers, participants struggled as a result of ambiguity in goals of care which arose in part from a lack of clarity surrounding a palliative care approach among health care providers and the family, potentially delaying the initiation of palliative care. Chittenden, Clark, and Pantilat (2006) have cited that interventionalist care that failed to take into consideration the goals of care or the effectiveness of these interventions on overall prognosis, could subject patients to ineffective or inappropriate interventions, as well as deprive patients/families from making decisions based on their values.

5.4 Weaving through the Tangled Web to get EOL Goals of Care

In this study, acknowledging that death was approaching and obtaining a consensus to transition from curative to comfort care goals, was a challenging process that took time. Unclear goals of care resulted from the difficulty in prognosticating when patients with medical conditions were at EOL and a culture of care on the medical unit that was focused on curative goals and interventions. Participants described patients as medically complex, often elderly, and possessing more than one chronic condition. While diagrammatic representations of illness trajectories have been beneficial in demonstrating the underlying pattern of decline when dying from one of multiple causes (malignancy, organ failure, frailty) (Lynn, 2001), these trajectories are limited in their ability to assist in prognosticating EOL for patients with chronic organ failure who are in recurring cycles of exacerbation and recovery (Pereira & Associates, 2008). With

advancing age and improvement in medical technologies, more patients are living with multiple chronic conditions and do not fit within one standard trajectory of illness (Murray et al., 2005). Studies of patients dying of organ failure have demonstrated that they have needs that would benefit from palliative care (Claessens et al., 2000; Lowey, Norton, Quinn, & Quill, 2013; McCarthy, Lay, Addington-Hall, 1996; Murray et al., 2002; Pere, 2012; Wotton et al., 2005), in some cases as early as the point of diagnosis. However the findings of this study, similar to other studies examining acute hospital care of patients who are dying, indicates that there is a lack of a palliative approach to care (Ferrand et al., 2008; Pincombe et al., 2003; Thompson et al., 2006a, 2006b; Toscani et al., 2005) or often palliative care is introduced late in the dying process when dying is finally acknowledged, if at all (Borbasi et al., 2005; Ferrand et al.; Toscani et al.).

In situations where the process of dying is not acknowledged, open communication, preparation for dying, and meeting the supportive needs of patients and families are hampered (Clarke & Ross, 2005). In the current study, the difficulty in diagnosing approaching death and the fear of premature withdrawal of treatment resulted in the pursuit of aggressive therapies until late in the dying process. Participants advocated for what they felt was in the best interests of the patient. Nurses perceived interventionist care to be futile at this junction. The insertion of tubes, frequent bloodwork, and other uncomfortable treatments (non-invasive ventilation such as BiPAP®), did not appear to be improving the patient's condition and often were seen as contributing to the needless suffering of the patient. In a study of ICU nurses' experiences with the withdrawal/withholding of treatment, Halcomb, Daly, Jackson and Davidson (2004) found that nurses perceived the continued pursuit of active treatment to be "burdensome" and contributed to the patient's "unnecessary suffering" (p. 218).

As the patient's condition deteriorated, it was more difficult to meet needs for comfort. Participants often encountered resistance from the medical team to consider a change in the treatment plan. They perceived the lack of discussion of the goals of care as partially originating from a physician-based medical model of practice that focused on curative goals and viewed death as failure. Participants' holistic view of the patient's response to illness, the desire to avoid suffering, and a view of death as part of life, often made it difficult for nurses and physicians to find a common ground in discussions about the goals of care. First year residents and medical students in particular, as inexperienced learners, were felt to be susceptible to wanting to continue to treat despite a lack of response on the part of the patient; this was attributed by the participants as originating from a general discomfort with death and dying and a lack of preparation in medical school in learning how to let people die. While these observations were made from the perspectives of nurses in this study, studies of physician, resident, and medical student populations support these observations of medicine's curative mentality (Calam, Far, & Andrew, 2000; Chittenden, Clark, & Pantilat, 2006), the perception of death as failure (Calam et al.; Chittenden et al.; Rhodes-Kropf et al., 2005; Schroder, Heyland, Jiang, Rocker, & Dodek, 2009) and the discomfort with discussions related to death and dying (Calam et al.; Chittenden et al.; Rhodes Tindall, Xuan, Paulk, & Halm, 2014).

The findings of this study revealed that in many cases, a patient's death occurred after a period of decline or unresponsiveness to treatment. However, participants felt that decision-making about EOL goals of care occurred late in the dying process after treatment options were exhausted. Often families were unable to connect with the medical team or were unaware or unaccepting of the patient's prognosis. Cherlin et al. (2005), in a study of patients with cancer who went on to receive hospice care, identified similar barriers to effective EOL communication.

They found that many discussions about EOL took place late in illness progression and that lack of effective communication stemmed from both an absence of discussions with physicians and the family's "difficulty comprehending and accepting bad news" (p. 1176).

The system of medical hierarchy was also seen as influencing communication and plan of care discussions. The personal philosophy of staff physicians set the direction for treatment and decision-making and what conversations with patients/family would take place. This is supported in other studies in which medical decision-making was based on the hierarchy within the team; the direction and preference of the staff physician and influence of team dynamics (Ahern, Doyle, Marquis, Lesk, & Skrobik, 2012; Farnan, Johnson, Meltzer, Humphrey, & Arora, 2008; Gorman, Ahern, Wiseman, & Skrobik, 2005; Rosenbaum, Bradley, Holmboe, Farrell, & Krumholz, 2004; Stevens et al., 2002; Ventres, Nichter, Reed, & Frankel, 1992). Although the participants described that it was the residents and medical students with whom they interacted on a daily basis, they did not feel that residents were predisposed or prepared to have challenging EOL discussions. EOL conversations with family were viewed by the participants as centering on interventions, rather than determining patient and family wishes for goals of care. In addressing resuscitation status in particular, the manner in which options were presented was found to be leading, or content failed to adequately present the outcomes of these interventions on quality of life. Several studies of resident experiences with EOL situations have shown that medical residents do not feel prepared to lead discussions with patients surrounding EOL issues (Gorman et al.; Stevens et al.; Ury, Berkman, Weber, Pignotti, & Leipzig, 2003), lack beneficial feedback/adequate supervision or role modeling in having these conversations (Buss, Caleb, Switzer, & Arnold, 2005), and desire more EOL clinical learning experience (Stevens et al.). In a study by Buss, Caleb, Switzer and Arnold (2005), an increase in clinical experience/exposure to

EOL was found to increase medical residents' self-perceived confidence with discussions related to EOL decision-making; however the quality of these conversations was often found to be suboptimal with few residents regularly eliciting the patient's values and goals as part of these discussions.

5.5 Interprofessional Relationships

An interprofessional team approach to care was found lacking in this current study. The environment of care influenced how interprofessionals worked, communicated and interacted with each other. It also affected the frequency and quality of the interactions between HCPs, patients, and families. In their place at the bedside for eight to 12 hours, participants were aware of the issues of the day, and had the most interactions with the patient. The medical team, particularly residents, were described as providing episodic care within the patient's illness trajectory. Residents often did not experience the history of hospitalization, or have as intimate knowledge or relationships from previous unit stays. With their individualized patient knowledge, nurses could have contributed to the discussion regarding the goals of care, but were unable because they were not part of the decision making team. Therefore they were stuck in the web trying to move forward and engage as part of an interprofessional team that was not working together and did not share a common goal.

The participants described that hierarchies within the organization related to communication and decision-making affected how medical teams were structured and how nurses communicated with the team. No formal processes existed which encouraged daily, direct collaboration between nurses and physicians. In addition, the constant rotation of residents, staff physicians, and specialists within the environment of care created challenges related to communication, continuity, and the formation of relationships between HCPs. These findings are

consistent with other studies of the effects of the medical environment on EOLC (Costello, 2001; McDonnell et al., 2002; Pincombe et al., 2003).

In this study, interdisciplinary relationships between nurses and physicians were found to be lacking in terms of collaboration and communication, particularly when there was a lack of consensus on the goals of care. An interprofessional team approach is considered an attribute of palliative care (Meghani, 2004), and is included as an integral part of palliative care delivery models (Ferris et al., 2013) and standards of practice (Canadian Hospice Palliative Care Nursing Standards Sub-committee, 2014; Canadian Palliative Care Association Nursing Standards Committee, 2001). Kalisch, Weaver and Salas (2009) have suggested that the “importance of effective teamwork in nursing and healthcare cannot be overemphasized” (p. 298). Effective team work has been linked to decreased stress (Adams & Bond, 2000), high quality patient care (Callahan et al., 2006; Rosenstein, 2002), less errors (Catchpole et al., 2007; Morey et al., 2002), patient satisfaction (Campbell et al., 2001; Hickson & Entman, 2008; Larrabee et al., 2004; Meterko, Mohr, & Young, 2004) and job satisfaction (Chang, Ma, Chiu, Lin & Lee, 2009; Rosenstein). Other studies have shown that communication and collaboration between physicians and nurses is often inadequate (Nathanson et al., 2011; O’Leary, Ritter, et al., 2010; O’Leary, Thompson, et al., 2010; Thomas, Sexton, & Helmreich, 2003) leading to a lack of mutual understanding of the plan of care and an overreliance on the medical record for obtaining information (O’leary, Thompson, et al.).

While nurses seek collaborative relationships with physicians, physicians are less likely to view nurses as colleagues or collaborators (Weinberg, Miner, & Rivlin, 2009), particularly in hospital based systems which support hierarchical communication processes and behaviours (Costello, 2001; Crawford, Omery, & Seago, 2012; Pincombe et al., 2003). Weinberg, Miner,

and Rivlin's (2009) study into physician's perceptions of their relationship with nurses found that most residents viewed the nurses' role as peripheral or supportive to that of the physician. Nurses functioned primarily as the conduit to carrying out physician orders, not as contributors to the plan of care (Weinberg et al.). With a constant rotation of physicians, residents, medical students, group dynamics are challenged (Hall & Weaver, 2001). Differing intradisciplinary views, language and desired goals can make it difficult to find a common ground (Hall & Weaver).

Participants in the current study were often not notified of the content and outcome of important communications between physicians and patients/family, were unaware of the goals of care, and were frequently absent at pivotal discussions that occurred between the interprofessional team and the patient/family at formal family meetings. A lack of interdisciplinary teamwork and communication led to feelings of disrespect among some nurses. As the primary providers of care, nurses have the most direct contact with patients and families and therefore are often the first to become aware of lack of response, or deterioration in the patient condition (McMillen, 2007). They often function as coordinators of care and facilitators of communications in linking patients, families, physicians and other HCPs. In their systematic review of studies associated with nurses' roles in EOL decision making, Adams, Baily, Anderson, and Docherty (2011) identified three roles assumed by acute care nurses at EOL: "information broker", "advocate", and "supporter" (p. 2). As information brokers, nurses acted as important intermediaries to aid communication both within families and between family members, physicians and other HCPs. Nurses gathered and relayed information, prompted discussions, and invited other HCPs to participate in EOL discussions (Adams, Baily, Anderson & Docherty, 2011).

In the organization of hospitals, physicians often function as gatekeepers to information, resources, decision-making and the goals of care. Participants in this study were reliant on physicians for access to an EOL plan of care. While nurses could consult services essential in managing acute care needs (rapid response team), they were unable to likewise consult the PCCS, for the needs of patients who would benefit from a palliative approach to care. Due to the absence of a common goal for EOLC and limited team communication and collaboration, nurses used their advocacy role to meet the patient's needs. Participants utilized their skills as advocates to challenge the physicians regarding the benefit of curative goals and to get access to the tools they needed to promote the comfort of the patient. In a review of the literature on nurses' role and strategies in EOL decision-making, similar to findings in the current study, Adams et al. (2011) described nurses' advocacy role as one of "challeng[ing] the status quo" on behalf of the patient towards either the family and/or physicians, most often regarding the goals of care (p. 10). In this literature review, nurses in some studies directly brought their concerns to physicians, used reporting, asked questions or indirectly made suggestions (Adams et al., 2011).

5.6 Providing Family Care

In this study, a key aspect of the nurse's role at EOL was in acting as a guide to families in preparing them for the physical changes and symptoms that often accompanied the dying process and could be distressing to witness. Nurses sought to educate families to minimize fear and anxiety and address misconceptions that could hinder care. The inclusion of family, either through physical means or emotional support, was also identified as an important component of EOLC in other studies (da Silva, Moreira, Leite, & Erdmann, 2012; Namasivayam, Orb, & O'Connor, 2005; Ranse, Yates, & Coyer, 2011). Advocacy and information were used by participants to update the family on the patient's condition and to determine the patient's and

family's expectations of treatments (in order to bring them to a realization). Once the patient was transitioned to comfort care and their comfort needs were met, nurses' focus then shifted primarily to the family (Fridh, Forsberg, & Bergbom, 2009; Thompson et al., 2006a, 2006b).

In this current study, caring for the family was viewed as both a challenging and integral part of EOLC for nurses. Participants were cognisant of their ability to impart a lasting memory of the experience of dying on the family and felt responsible for orchestrating this seminal event. Families could require a wide range of supportive needs as they experienced transitions along with the patient - from expectations for cure, to the realization of the lack of improvement, and then accepting of a shift to EOLC. Families could experience denial, anger, anxiety, confusion, and grieving among other strong emotions. However, family dynamics could add another level of complexity to nurses' supportive care as each family member reacted differently to the patient's declining condition thereby requiring differing supports and intra-familial conflict could also be present affecting care and decision-making. Similar to other studies (Badger, 2005; Kirchhoff & Beckstrand, 2000; Thompson 2006a, 2006b), participants described many instances of encountering conflict with the family in EOLC transitions; conflict surrounding the goals of care and the family's desire to pursue curative treatment despite the patient's physiologic decline and approaching death. Rhodes Tindall, Xuan, Paulk, & Halm, (2014) found that the family's lack of knowledge regarding the patient's illness was often a barrier to EOL discussions.

HCPs have a significant impact on the satisfaction of families and their experiences at EOL (Jackson et al., 2012). In studies of family perceptions at EOL, families evaluated good nursing care through the nurse's ability to tend to physical care of patient (da Silva et al., 2012; Hawker et al., 2006), maintain good pain and symptom management (da Silva et al.), be available (da Silva et al.; Hawker et al.), show attention (da Silva et al.), and promptly respond to

needs (da Silva et al.). Participants in this study used caring behaviours and supportive strategies such as reassurance, checking in, and being present as part of their care of the family which were similar to strategies identified by Thompson et al. (2006a, 2006b) and da Silva, Moreira, Leite, and Erdmann (2012). Checking in was used as a means of providing a reassuring presence to family, being visible and to determine if the family had any needs. Similar to studies in critical care environments, nurses in the current study used their physical presence to support families, as well as taught family ways they could be present with their loved one through talking and touching (Fridh et al., 2009; Ranse et al., 2011; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtmann, & Gagnon, 2011). Thompson et al. (2006b) found similar findings in their theme “being there” where nurses valued being physically and emotionally present to support families, however, these efforts could be hampered if dying was not acknowledged or nurses were kept away due to managing “crises” on the unit (p.173).

Care of the family took time and simple gestures were used to convey interest and attention, such as sitting down, listening, and being engaged. Spending time, listening and being available to the family was also identified as supportive behaviours used by nurses in acute and long-term care settings (Namasivayam et al., 2005), however, similar to this study, nurses felt restricted by lack of time and workload in being able to adequately care for families (Namasivayam et al., 2005; Thompson et al., 2006a, 2006b).

Building relationships with families, fostered through communication, is an essential part of providing quality EOLC (da Silva et al., 2012). Research has shown that families value honest communication (Jackson et al., 2012), being informed (da Silva et al.; Hawker et al., 2006; Jackson et al.), and expressed feeling reassured when staff was perceived as being caring (da Silva et al.; Hawker et al.; Jackson et al.). However, in this study, there were barriers to building

relationships. The busy nature of an acute care unit and the prioritization of physical needs, acted as barriers to psychosocial care. In addition, the number of health care providers involved in a patient's care, the rotation of medical staff, and the nature of nurses' shift work posed a challenge to consistent messaging, communication and continuity. In Hawker et al.'s (2006) study of EOLC in community hospitals, the familiarization of the family with nursing staff, particularly in situations where the patient had a "long history of care" at the institution, allowed for the formation of relationships between staff and the patient/family which enhanced continuity of care and good communication (p. 544). By getting to know the patient and family, an important factor in family care, nurses were able to become acquainted with the "little things" that gave the family reassurance that the patient was "well looked after" (Hawker et al., p. 544). The importance of forming relationships and the time required to assess and provide for the holistic needs of patients and families is often under recognized and not built into nursing workload (Ranse et al., 2011).

5.7 The Intraprofessional Work of Nurses: An Intraprofessional Network of Support

The findings of this study demonstrated the essential role a strong intraprofessional nursing team played in supporting unit function, personal and professional development and patient/family care at EOL. At the unit level, supports were built into creation of patient assignments, the availability of nurse educators and managers, and in the identification of experienced nurse colleagues to help manage patient care issues. The main source of support however, was generated from the relationships between bedside nurses themselves; a banding together during times of acuity, challenge and workload. Hopkinson et al. (2005) study similarly found that "helpful relationships" between newly qualified nurses and nursing colleagues facilitated coping, particularly in obtaining advice in clinical decision-making (p. 128).

Intradisciplinary relationships have the capacity to provide comfort in connections created with those who share similar experiences, values, approaches and comprehension of the issues (Hall & Weaver, 2001). In a survey of nurses working in 17 hospitals (acute adult wards) in England, Adams and Bond (2000) found that of all working relationships (physicians, HCPs, management, nurses), intraprofessional relationships were the most important for nurses, with a “cohesive” nursing staff having the strongest effect on job satisfaction (p. 542). These findings were supported in Utriainen and Kyngäs’ (2009) literature review of factors affecting nurses’ job satisfaction, which determined that intraprofessional relationships and patient care had the most significant impact. In a study by Newman and Maylor (2002), nurses identified patients and staff as being important to them, more so than commitment to the organization, since these relationships in the direct working environment “form the universe of work, of friendships, and social networks” (p. 85).

The emotional support of colleagues was a significant facilitator in EOLC and coping for the participants. Studies have shown that nurses are more likely to use informal support networks of nurse colleagues (Badger, 2005; Halcombe, Daly, Jackson, & Davidson, 2004; Jones & FitzGerald, 1998; McClement & Degner, 1995; Ranse et al., 2011), than seek formal assistance (Badger, 2005; Halcombe et al.; Ranse, et al.). Haavardsholm and Naden (2009) discussed the importance of the presence of a “professional network of coworkers” which fostered confidence and security for nurses in their practice (p. 483). Through trusting relationships with colleagues, nurses felt supported and valued; they could share their experiences, talk to one another, rely on each other when work became demanding, handle issues as a team, and feel that they did not shoulder the burden alone (Haavardhold & Naden, 2009).

5.8 Achieving Comfort for the Patient

For participants in this study, provision of comfort was a source of personal and professional satisfaction. Importance was placed on meeting the foundational basics of good physical care (the physical needs and symptom control). The aesthetics and appearance of comfort for the patient was also a source of comfort for nurses and families and was used by both as a means of demonstrating and evaluating for the presence of good nursing care. These findings are supported in the literature (da Silva et al., 2012; Hawker et al., 2006, Ranse et al., 2011). Equipment and medical tubes that did not contribute to comfort were removed. Interventions were employed to make rooms more calm and private in order to shield patients and families from the chaos of the medical unit. Modifying the environment, to promote comfort and privacy for the patient and family, were frequently mentioned in other EOL studies (Ranse et al.; Thompson et al., 2006b) which included the removal of equipment and personalizing the bedside to create a more humanistic atmosphere attuned with the idea of comfort that was focused on the patient rather than the medical aspects of the hospitalization (Ranse et al).

Providing comfort, for participants, was more than just meeting the needs for physical care. Emotional comfort could be provided through various modes including physical means, presence, and from emotional support. Emotional comfort was enhanced through the use of subtle behaviours employed by the nurse, such as through talking/tone of voice, the slowing of movement, and the use of touch. One participant in the current study identified the power of human touch (Anne), and several nurses identified attempts to slow their movements as part of their comfort strategies. These findings are in line with the concept of comfort (Kolcaba, 2003; Lowe & Cutcliffe (2005); Morse, 1992; Siefert, 2002) and comfort measures (Oliveira, 2013). Comfort is multidimensional in nature and may be experienced as a result of needs being met in

several interconnected domains including the physical, psychospiritual, social, and environmental realms (Kolcaba). Therefore, comfort measures employed in one realm (e.g. physical), have the capacity to affect a greater response on comfort in other realms (e.g. emotional comfort) (Oliveira). The use of touch (Bottorff, Gogag, & Engelberg-Lotzkar, 1995; Chipman, 1991; Fleming, Scanlon, & D'Agostino, 1987; Kolcaba; Morse; Shoenhofer, 1989; Sumner, 2008; Waldrop & Kirkendal, 2009) and voice (Chipman; Morse) have been described as comfort measures in the nursing literature.

In the current study, small gestures or “little things” referred to those tasks which were often directed at meeting the basic physical needs of the patient; despite being considered small and basic, these gestures could elicit a powerful response in the patient. These ‘little things’ often brought about a sense of wellbeing, and were frequently the source of creating memorable moments between nurses and patients. The meaningfulness of “little things” and their effect on patient comfort has been demonstrated in several studies (Arman & Rehnsfelt, 2007; Perry, 2009a; Perry, 2009b; Sumner, 2008; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman et al., 2011). The power of the “little things” lay in that they showed the nurse’s effort, caring, and attention (listening) (Sumner). In Arman and Rehnsfeltdt’s study (2007) of good nursing care, the authors identified the importance of “little extra[s]”, as it demonstrated nurses going “beyond the routine” to provide individualized care and showing respect; while for patients it meant being “seen” as a person instead of a diagnosis and was interpreted as a sign of nurses’ commitment to them, which was a source of emotional comfort (p. 376-377). Participants in Sumner’s (2008) study suggested that providing comfort through the little things required taking time, and demonstrated a higher level of expertise than the technical tasks involved in care. As Sumner

suggested, nursing care is “concerned with the solace of the human condition, and it is the little things expertly provided to patients that ensure this” (p. 96).

Participants in the current study described the importance of being present for patients as a way of providing emotional comfort. They used their voice to reassure patients, even when unconscious, that they were not alone and to signal the presence of loved ones in the room. One participant described wanting to be with the patient at the time of death, so that the patient did not die alone. Presence has been described as more than physical proximity to another person (Thompson, 2005), it is a means of “being with” another person (Benner, 1984. p.57), and has been associated with compassion and caring (Covington, 2003). Being with a patient can involve listening, conversation, and touch (Benner). In her meta-synthesis on presence, Finfgeld-Connett (2006) found that presence was an interpersonal process that involved “being with another person in an intimate way” and included additional attributes of sensitivity, holism, vulnerability and uniqueness (p. 710-711). Due to the complexity involved with being present, it has been suggested that to be present requires “personal and professional maturity” (Finfgeld-Connett, 2006, p. 711). Finfgeld-Connett suggested that being present also required a conducive environment characterized by sufficient time, adequate staffing, colleagues who are supportive, and the judgment to balance tasks/technology with psychological/spiritual matters. Thompson et al. (2006b) indicated that nurses must be comfortable with dying in order to be “present” for patients (p.173).

5.9 Learning EOLC on a Medical Unit

The majority of participants described learning to provide EOLC as occurring primarily through their clinical experience. It was through experiential learning that one participant described his “blinders” coming off resulting in a broadened perspective of EOLC. Novices in

particular identified limitations when attempting to transfer knowledge obtained from formal education or textbooks. Preparation through reading did not capture the profound experience of working through and supporting the individual emotional response of patients and families facing EOL. The expectation to be able to walk into a patient's room and feel prepared to manage the holistic needs of a patient/family unit facing death could be a daunting task. Nurses in the current study used words such as "thrown in" or having to "jump in" to describe either their voluntary or involuntary (yet inevitable) exposure to the uncertainty of EOLC. In her study of newly qualified nurses' experiences of providing EOLC on medical units, Hopkinson (2001) found that novice nurses perceived that they had deficits in their EOL skills, knowledge, and experience which led to feelings of inadequacy. The term "thrown in" was also used in Hopkinson's study to describe how novices felt trying to deal with the psychosocial elements of EOLC (such as communicating or how to be with patients/families at EOL). In the current study, participants that were novices described needing to be ready to "hit the ground running". Part of "hitting the ground running" was related to learning within the demanding medical environment. The context of care brought a new dimension to EOLC. Novices were required to negotiate the tangled web, just as more experienced nurses did, but without the same degree of knowledge, confidence and expertise. Participants were required to advocate and make decisions within complex interpersonal dynamics, time constraints, workload and variable resources. In order to obtain tools to provide EOLC, participants needed to learn to be effective advocates which required them to be persistent, knowledgeable, confident and possess good communication skills to express what they needed. Experienced and novice participants alike in the current study described the difficulty they faced in being comfortable enough to challenge physicians and navigate these relationships as part of being a patient advocate. Studies of novices have found

that interactions with physicians were generally very stressful, could create anxiety, and affect self-confidence (Andersson & Edberg, 2010; Delaney, 2003; Dyess & Sherman, 2009).

Andersson and Edberg (2010) described how novices needed courage in order to question the orders of physicians, while Dyess and Sherman (2009) described how poor communication with physicians, or a physician's dismissive attitude, could impact confidence when novices were attempting to advocate.

In the current study, mentors helped novices navigate through the tangled web of EOLC by providing: assistance with decision-making, advice, support, and information as well as informal debriefing in emotional situations. The availability of mentors to provide guidance for both learning and coping was a key resource for novice participants who were attempting to consolidate and adapt classroom knowledge to the individual context. Expert nurses also provided a supportive role on the unit for the participants by assisting in managing workload or by covering call bells to free up time for participants to spend time with families who needed support. In a study by Duchscher (2008), novices reported higher levels of stress in situations where they were caring for patients who were dying and trying to juggle multiple patient/family issues and tasks (processing physician orders, etc.) while simultaneously providing direct bedside care. The literature identifies that support and daily guidance (Leners, Wilson, Connor, & Fenton, 2006) by expert nurses is needed to assist novices in their knowledge transfer (Jewell, 2013; Morrow, 2009). This is particularly important as novices often feel overwhelmed, isolated and under supported (Delaney, 2003; Duchscher, 2008; Dyess & Sherman, 2009).

Although studies have found that staff nurses do not feel adequately prepared to provide EOLC (Dunn et al., 2005; McDonnell et al., 2002; Thacker, 2008; White et al., 2012) or lack education on palliative care principles (McDonnell et al.), experienced participants in this study

felt comfortable assessing and managing the physical and symptomatic needs of the patients at EOL. Through experiential knowledge, these nurses knew the tools they needed to care for patients (privacy, medications, consultations, equipment); the challenge was in obtaining access to these tools of care. Experienced participants in the current study, in general, did not point to the need for more education to be able to perform their role at EOL, but in needing the personal and professional supports to do so. The importance of clinical experience in gaining EOL knowledge and skills has been identified by nurses in several EOL studies in medical environments (Clarke & Ross, 2005; Hopkinson et al., 2005; Wallerstedt & Andershed, 2007) and critical care (Fridh et al., 2009). Fridh, Forsberg and Bergbom (2009) found that nurses in their study learned EOLC through their colleagues as well as “personal experience as opposed to guidelines and scientific knowledge” (p. 240). This was necessary as every patient/family was unique and their circumstances individual. Clarke and Ross (2005) found that through experience, one learned “to play it by ear” in communicating with patients who were dying, however, medical nurses who lacked experience were hindered in these communications (p. 38). Communicating with patients regarding death and dying can be difficult (Betcher, 2010; McDonnell et al.; Sasahara et al. 2003), and being able to adequately support the psychosocial needs of patients and families can be challenging. Duchscher (2008) found that supporting families who had many questions or were considered demanding was highly stressful.

Novices in the current study expressed anxiety about saying the wrong things and were concerned whether they were adequately meeting the patient’s/family’s needs. Mentorship by experienced nurses provided a means of developing and adapting knowledge into an individualized EOLC context (within a safe and supportive relationship). Mentorship incorporates aspects of support, guidance, empowerment (Carroll, 2004; Greene & Puetzer,

2002; Management Mentors, n.d.; MentorSet, 2008; Ronsten, Andersson, & Gustafsson, 2005) and has been found to be helpful in building confidence and competence in the learner (Ronsten, et al.). Ronsten, Andersson and Gustafsson (2005) found that through formal mentoring, novices increased their ability to evaluate individual patient situations, have a more holistic perspective to their care as well as increase their collaborative relationships. Mentorship may be particularly helpful in situations, such as those presented within an EOL scenario, “where there is a lack of clarity or a difference of opinion regarding how to proceed” (Ronsten et al., p. 313).

6.0 It’s a Privilege

Nurses described caring for patients at EOL on a medical unit as weaving through a tangled web. One begins to question, why do nurses continue to work in this tangled web where there are unclear goals of care, limited resources and they are at times marginalized from interprofessional team dynamics and decision-making? Participants expressed a personal, professional and moral responsibility towards the patient and family in trying to provide the best possible experience of dying under what was generally considered less than ideal circumstances. Many participants derived personal comfort in knowing they had done what they felt was the best that they could do for the patient and family. Doing one’s best included: providing a supportive environment, ensuring comfort and allowing an opportunity for the patient and family to spend meaningful time together as death approached. For these nurses, the act of caring for a patient who was dying was of equal importance as caring for patients for whom cure was still possible. Being a part of a patient’s EOL journey was considered rewarding, and ultimately, a privilege. It was the negotiating of EOLC for patients that was difficult, not the provision of that care. Participants were conscious of their ability to imprint a lasting memory, and were driven by their compassion and empathy to care for these patients and families as they would want

themselves or their own loved ones to be cared for. These findings were supported in Fridh et al.'s (2009) study where nurses expressed wanting to attach a consoling final memory to the EOLC experience for families, that their loved one was "cared for" and in nurses having "done a good job" (p. 235).

The association of providing nursing care to a patient and family at EOL with being a privilege is a sentiment that has been expressed by nurses in other studies of EOLC in critical care environments (Fridh et al., 2009; Ranse et al., 2012; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman et al., 2011). Fridh et al.'s (2009) study of ICU nurses' EOL experiences identified "doing one's utmost" to care for the patient and family as the main theme of their study. Similar to the findings of the current study, the authors described how nurses did their best to afford the patient a dignified death, promote comfort, and overcome environmental barriers to provide an "enduring memory" of the EOL experience for the family (p. 233, 235). Fridh et al.'s study illustrated the impact that the perception of having done a good job had on nurses' coping; dying events that were viewed as having gone "well", allowed nurses to have a clear conscience, which facilitated the nurse's recovery from some of the draining aspects of EOLC and enabled them to "move on" to care for other patients (p. 238).

Participants in the current study felt a personal reward and sense of fulfilment arising from the emotional connections they made with patients and families at EOL. Good nurse-patient relationships and connecting with patients has been found to be associated with job satisfaction (Perry, 2005; Sumner, 2008; Utriainen & Kyngäs, 2009). In a study into the factors contributing to nurses' professional fulfilment, Perry (2005) found that nurses who made "strong connections" with patients and felt that were able to deliver high quality care were "very satisfied" with their job (p. 43). Nurses felt fulfillment when sharing intimate moments with

patients and families in which they felt they had made a difference. “Deep human connections” were made as a result of “affirming the value of the person, defending dignity, enabling hope, and helping them to find meaning in the illness experience” (p. 43). While acknowledging that relationships are normally built with time, Perry highlights that connections may occur through brief moments facilitated through actions as simple as listening, touching, or talking. Making a positive difference in a patient’s care, promoting wellbeing, preserving dignity through advocating for those who could not advocate for themselves, and doing good were other sources of significant satisfaction for nurses (Perry; Sumner, 2008).

6.1 Implications for Nursing Practice, Education and Research

The findings of this study have relevance for nursing practice, education and research. Implications of the findings and recommendations for future work are presented as well as the limitations of the study.

6.1.1 Nursing Practice

The findings of this study suggest the presence of experienced nurses is essential to the healthy functioning of the medical unit on several levels in order to provide quality EOLC. Experienced nurses demonstrated how to navigate relationships, obtain resources and facilitated novices in the learning of EOLC. The Canadian Nurses’ Association and Canadian Association of Medical Surgical Nursing have recognized medical-surgical nursing as a specialized area of practice (CAMSNS, 2008; CNA NurseOne, n.d.). Nursing leadership within medical units must take steps to recognize the contribution of experienced nurses and the specialty of medical surgical nursing. Organizations should provide resources to assist nurses with their personal and professional development as a means of continuing to enhance their expertise. Resources are required for nurses to prepare and pursue specialty certification in medicine, provide continuing

education opportunities, as well as include nurses in quality improvement projects and empower nurses by including them in unit leadership opportunities (e.g. unit councils) in order to address unit issues and improve the environment of care.

The participants in this study recognized the importance of their nursing colleagues in supporting them through the challenges of providing EOLC on a medical unit. With fewer human and financial resources available to assist with care on inpatient units, the need for high functioning, supportive nursing teams will become critical to manage the day to day complex needs of patients/families and maintain demanding unit routines. Research has identified the importance of cultivating supportive nursing relationships at the unit level. However, current workloads and work environments may make it challenging to sustain intraprofessional relationships. Adams and Bond (2000) suggest the maintenance of cohesive nursing teams requires a stable core of staff which has implications for staff retention.

Nurses in this study derive satisfaction both in their perception of being able to give quality care and in making connections with patients and families (Utriainen & Kyngäs, 2009). The inability to provide “quality nursing care” has been shown to cause nurses to experience role stress particularly when perceived to be arising as a result of lack of time (Chang et al., 2005, p. 31). The culture of hospital care that identifies the completion of tasks as work (Clarke & Ross, 2005; Pearcey, 2010), and under-recognizes the value of relationships needs to be challenged within unit and organizational leadership. Hospitals must also recognize the important invisible work of nurses. The “little things” and psychosocial care must be considered and built into nursing time as workload within nursing assignments.

Participants’ described being left out of important communications about prognosis, plan of care, and felt lack of inclusion in decision-making. Nurses can play an important role in EOL

decision-making including assessing patient/family's understanding of disease process, goals of care, as well as broach discussions regarding patient wishes about EOLC. An important first step to nurse inclusion in EOL decision-making would be an organizational expectation that nurses be part of family meetings. Structured family meetings may be one method of bridging the communication gap and developing a shared understanding between HCPs and families in discussions about EOL.

Practice issues resulting from inadequate interdisciplinary communication and collaboration were identified in this study. Interprofessional communication has been found to be important in ensuring patient safety (Leonard, Graham, & Bonacum, 2004) and has been identified as an important aspect of quality EOLC by HCPs, patients and families (Carline et al., 2003; Curtis et al., 2001). A multifaceted approach is required to improve teamwork and communication (Shannon & Myers, 2012). An organizational culture and supportive leadership focused on teamwork, communication and patient safety (Shannon & Myers) is required as well as the "flattening of hierarchies" which empowers nurses to be able to "speak up" and be heard in nurse-physician interactions (Leonard et al.; Shannon & Myers). Leadership workshops could be held for nurses to help them learn to speak up to have their voice heard. The establishment of interprofessional teamwork and collaborative relationships in the practice environment is also needed. Organizations can foster these relationships through processes which promote face to face communication such as team rounds (nurse/physician bedside rounds) (Burns, 2011), team huddles (Shannon & Myers), or briefings (Leonard et al.). Nurses in this study also identified their restricted access to formal palliative care resources as a barrier to EOLC. A potential solution was proposed by Nelson et al. (2011) who suggested that the development of criteria to

initiate palliative care services may be a more reliable means of consultation than an individual practitioner's discretion or dependence on one's abilities of persuasion.

6.1.2 Education

This study has illustrated the complexity of caring for patients at EOL on a medical unit. The participants described the power of learning from clinical experience and that classroom and textbook knowledge was not adequate. Sufficient exposure to EOLC as part of student learning is required. Clinical education in EOLC must include a focus on acute settings and incorporating palliative care principles into this context. Students need to be taught the importance of good care in all settings. Educating nurses in ways of incorporating presence, the principles of "good care" (Vanderspank-Wright, Fothergill-Bourbonnais, Malone-Tucker, & Slivar, 2011) and psychosocial care into daily practice are required. Students need to be given ample opportunity to provide care such as bathing patients so that they can understand the impact of basic nursing care on comfort.

The participants described the process of transitioning patients from curative care to EOLC as weaving through a tangled web. Strategies for facilitating transitions with family and communicating with physicians should be part of palliative care education for staff. Ongoing education for staff related to family support and communication should also be made available (RNAO, 2002). Continuing education in the form of workshops, in which nurses may practice and share communication skills would be helpful. The opportunity to observe experienced nurses, other members of the interprofessional team as well as palliative care professionals in their practice and communications with patients at EOL, was seen as valuable in the development of knowledge and skills in other practitioners (Clarke & Ross, 2005; Hopkinson et al., 2005).

Furthermore, findings revealed that a variety of terms are used at EOL such as code status and level of care. Interprofessional dialogue and education needs to occur related to these terms so that all members of the team are using the same language. Organizations such as the CHPCA could be helpful in clarifying terms associated with palliative and EOLC.

6.1.3 Research

Chronic disease management involves negotiating many transitions including admission/discharge from hospital, transfers in and out of units of high and low acuity, and from curative to EOLC. Nurses can play key roles in facilitating these transitions and maintaining continuity of care. More research needs to be done about how nurses can effectively meet the supportive needs of patients/families through these transitions and promote safe patient care. The comfort work of nurses was a key component of EOLC and a source of personal satisfaction for many participants. More research needs to be done on how nurses provide comfort, what comfort care means to nurses and how comfort work is received by families.

The environment of the medical unit presents many challenges to consistency, communication, and teamwork. Health care/unit restructuring is often focused on achieving efficiencies which does not always support effective communication between interprofessional teams (Arford, 2005). More research is needed on how to support and structure health care environments so that they are conducive to interprofessional communication and collaboration. For example, a small study could be undertaken on one unit to try a different way of nurses and physicians communicating.

6.2 Implications for Advanced Nursing Practice

The findings of this study have relevance for advanced nursing practice. The Canadian Nurses' Association (CNA) Advanced Nursing Practice Framework (2008a) outlines four core

competencies of the advanced practice nurse (APN): clinical, research, leadership, and consultation/collaboration. Implications will be discussed within the context of these competencies.

6.2.1 Clinical

At the center of advanced nursing practice is the clinical practice core competency which constitutes a large proportion of the APNs role (CNA, 2008a). Advanced nursing practice involves the use of extensive nursing knowledge and expertise within a specialized area of practice to meet the complex needs of patients and families in partnership with nursing colleagues and other HCPs (CNA). The specialty of medical nursing, specifically the management of complex patients with chronic, progressive illness, represents an area of practice which would benefit from APN involvement.

Support of the family is one of the central tenets of palliative care (Ferris et al., 2013; Health Canada, 2009; Meghani, 2004; RNAO, 2011; WHO, 2002). Informational and emotional support of the patient and family is a large part of nurses' work at EOL. As a constant presence within the inpatient environment, the APN represents an opportunity to establish an ongoing trusting relationship with patients and families. Patients and families value communication and collaboration. The APN is positioned to assist patients/families in navigating through organizational systems, and promoting continuity in an environment where HCPs are constantly rotating through the patient's circle of care. With knowledge related to illness trajectories and models of early introduction of palliative care, the APN can provide patients/families with education regarding disease process, explain the supportive role of palliative care, as well as broach topics related to advance care planning within these established relationships. The role of the APN in these instances would not be to diminish the role of the bedside nurse or other HCPs

involved in care, but rather to be a support to the interprofessional team to improve consistency in communication, collaboration and reduce fragmentation in patient care.

The APN may also assist in facilitating transitions in goals of care from a curative to comfort focus. As demonstrated in this study, negotiating transitions at times involved working with families with complex dynamics. With their holistic view of the patient and health care systems, the APN could be a means of mobilizing available resources for managing these challenging situations or in advocating for the building of organizational supports if lacking (e.g. ethic consultative resources).

6.2.2 Research

Generating knowledge through conducting research, as well as accessing, synthesizing research for use in clinical practice is another role of the APN (CNA, 2008a). The APN can consult the literature and research on EOLC to promote evidence-based practice for nurses, develop strategies for incorporating a palliative care approach to care and advocate for organizational support for practice changes that challenge traditional hierarchical structures and processes.

The APN may also participate in interprofessional research that focuses on particular aspects of EOLC. For example, qualitative research could examine how the interprofessional team actually communicates with the family or each other when discussing patient care.

The formation of “unit-based” APNs to direct interprofessional teams as a method for creating an organizational environment which promotes improved team communication and a unified goal of meeting patient-centered needs has been recommended (Arford, 2005).

Investigating the outcome of this innovative approach of APN managed teams on collaboration,

fragmentation of care and patient/family satisfaction with EOL decision-making could be the focus of APN research at the unit level.

6.2.3 Leadership

As leaders and change agents within an organization, APN's proactively seek new means of enhancing practice and organizational systems to improve the quality of care (CNA, 2008). In their ability to recognize issues at the individual and systems levels, APNs may assume the role of advocate to affect change and improve access (CNA). This study has recognized that the setting utilized was lacking in a formalized palliative care approach. The APN may be instrumental in advocating for change in organizational culture where there is more clarity surrounding the palliative care philosophy, and the language used in practice (comfort measures, code status, palliative, EOL). The APN can advocate for organizational change and policies which encourage a blending of a palliative care approach into care earlier in chronic disease trajectories and facilitate systems to allow interprofessionals to access the PCCS.

The mentorship of fellow nurses and other HCPs is another role within the leadership competency of the APN (CNA, 2008a). Novice nurses in the current study have identified wanting guidance with supporting families and communication skills. Role modelling is one aspect of mentorship (Greene & Puetzer, 2002; Pulce, 2005) which would be beneficial for building expertise. Watching experienced nurses as they role model communication skills has been identified as beneficial to learning (Ross & Clarke, 2005). The APN can role model those skills in which novices in this study expressed a lack confidence such as communication, support of families with complex dynamics, advocacy and conflict resolution.

APN leadership also involves identifying and developing resources to meet the educational needs of nurses and other HCPs (CNA, 2008a). The APN, in consultation/

collaboration with the manager, educator and other health care team members can conduct a learning needs assessment of nurses and other HCPs related to EOLC. Potential topics of staff professional development workshops could include EOL communication and participation in goals of care.

6.2.4 Consultation and Collaboration

Nurses in the current study have identified that care of the medical patient is challenging. These patients often do not have a textbook presentation, have confounding comorbidities, and may not respond to treatment in a typical way. Standardized care and application of best practice guidelines can pose challenges. As one participant remarked, these patients required one to “think outside the box”. The APN role is ideally situated to collaborate and apply expertise in situations that do not have a definitive answer. Through collecting and synthesizing of knowledge from numerous sources (CNA, 2008a) such as through accessing literature/research, application of theories, and consultation with community partners, other APNs, specialists and experts, APNs may assist nurses and other HCPs in situations with complex clinical decision-making.

Patients with chronic organ failure illnesses such as COPD and heart failure often follow a path of multiple admissions or emergency room visits within the last year of life (CIHI, 2007). Though these diseases are often manageable in outpatient environments (Physician Hospital Care Committee, 2006), these patients often face difficulties associated with accessing services (Physician Hospital Care Committee) and coordinating care between multiple care providers (Cumbie, Conley, & Burman, 2004). APNs can help coordinate transitions between outpatient and inpatient services for these patients, as well as facilitate transitions as inpatients. The APN may also have a role in following the patient’s journey through hospitalization, providing

ongoing communication between specialties, with the larger picture of long-term goals of care in focus. APNs may also be consulted to support nurses and the interprofessional team in facilitating patients/families with complex EOL decision-making or in addressing complex family dynamics or conflict.

6.3 Limitations of the Current Research Investigation

The purpose of the current study was to seek to understand the lived experience of nurses providing EOLC to patients on a medical unit. The meanings derived from these interviews are influenced by the environment in which care occurred and the organizational structures of this particular hospital setting. Therefore, the findings of this study may not be reflective of nurses' experience in working in other medical units or other environments such as community hospitals, and non-academic hospitals. In addition, these findings may not reflect the experience of nurses working in mixed specialty units (medical/surgical), or single specialty environments.

Limitations related to sampling may have impacted the findings of the current study. The specific topic of EOLC may have led to nurses who have a particular interest in this phenomenon to volunteer and participate in this study. Experiences of other nurses, particularly those who may be uncomfortable with EOLC, would not be reflected in the study's findings and may have presented a different view of EOLC within the units under study. Another potential limitation of sampling was that all of the participants, except one, were recruited from study unit A, which was the unit containing the six bed monitored area. The researcher could not discern a reason for the difference in recruitment results. The recruitment strategies, availability of posters, and presentations were similar on both units and support of management was obtained for both areas. It is possible that the first interview of a nurse on unit A may have led to further recruitment from within that unit. It is not known if the effect of the presence of the monitored unit may have

brought a different dimension to the experience of negotiating transitions for patients at EOL in this study. One of the strengths of the current sample was in the variety of participants who were recruited; there was representation of novices, experienced nurses, and male participants (novice and experienced) which allowed and the results to reflect broader experiences.

Phenomenological research does not purport to capture the full range or understanding of the phenomenon under study, but rather the essence of the experience as lived from the perspectives of the nurses who participated. While small in scope, this study adds to our growing understanding of what it means to provide EOLC on a medical unit and sheds some light on the factors which can potentially help or hinder nurses in providing this care.

6.4 Conclusion

This study revealed that caring for patients who were dying within an acute medical environment can be challenging; particularly the process of transitioning patients from curative care to EOLC. The essence of the experience was likened to “Battling a Tangled Web”. The environment, the complexity of care for patients with medical conditions, and the relationships that were continually being formed and negotiated were all interwoven together and often resulted in tangled obstacles to providing EOLC. Participants played an important role in working through the barriers to EOLC in using information, advocacy and support to facilitate these transitions. Study findings also revealed the important and often subtle comfort work of nurses essential to EOLC, such as doing the “little things”, creating connections, use of presence, and the forming of trusting relationships with patients and families.

The findings of this study contribute to our understanding of the experience of nurses caring for patients at EOL on a medical unit; in particular the effects of the environment in influencing patient care and relationships. The need for organizational, personal and professional

support to be able to provide this care was identified. The importance of a cohesive intraprofessional team and the availability of nursing expertise were also revealed to be essential in helping nurses to persevere in finding their way through the web. Despite the challenges to providing EOLC in this environment, participants felt privileged to care for these patients and families and took pride in providing good care. Doing a good job left participants and families with the lasting impression that the patient had been well cared for, as Anne explains:

Because everything else that we have, I think when it comes-like all the bells and whistles, that's fine, ultimately what it's going to be is the nurse at the bedside with her soothing hand, holding that patient, and communicating with the family. That's what you really need....this is where human contact and compassion trump everything! Ok, yeah, we've got the oxygen, and yeah, we've got this-and all the medications and stuff like that...that's all part of it. But as long as I got those basics...what is going to make the biggest difference is the care that is going to be given to the patient, the physical care that's going to be given to this patient at this time. That, and the attitude that you have, that's going to make the biggest impact. 'Cause ...you've already lost the patient.....So, the impact you now have a chance, an opportunity, to leave an impression with the family that's going to last forever.

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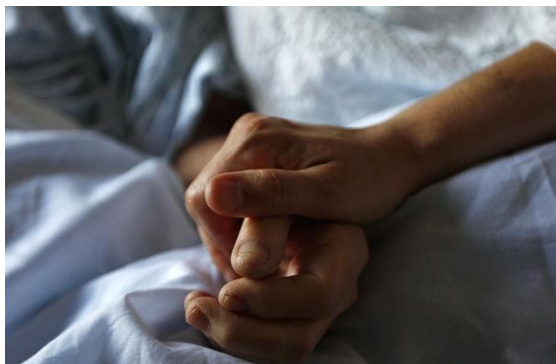
Appendix A: Recruitment Flyer (English)



Requesting Volunteers for a Research Study Exploring Nurses' Experiences in Caring for Patients at End-of-Life

Study Purpose and Aims of the Study:

The purpose of this qualitative study is to increase our understanding of what it is like to provide end-of-life care on a medicine unit and what helps or hinders the provision of this care.



Who Can Participate?

- Registered Nurses (RNs) working on 5 northeast/ 5 northwest for a minimum of 6 months
- Are comfortable communicating in English
- Have had an experience caring for patients who are receiving end-of-life care on a medicine unit.

This study is being done by Irene Oliveira, a Registered Nurse and a Master of Science in nursing student at the University of Ottawa under the supervision of Dr. Frances Fothergill Bourbonnais, Emeritus Professor in the School of Nursing.

What is involved?

You will be asked to take part in two interviews with the researcher Irene Oliveira: the first will be 30-60 minutes in length and the second will be about 20 minutes. The interviews will be done at a time and place convenient to you outside of shift hours and will be audiotaped.

If you are interested in participating please contact Irene Oliveira for more information.

Your participation in this research may contribute to our understanding of the provision of end of life care on medical units.

This research study has been approved by The Ottawa Hospital Research Ethics Board

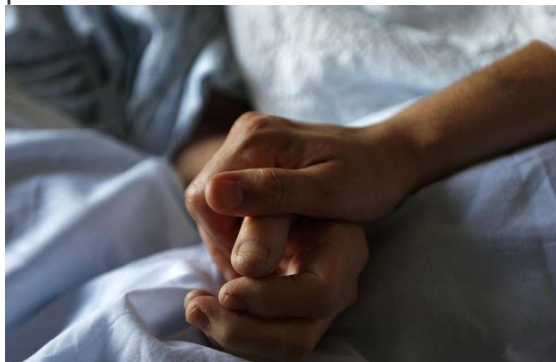
Appendix B: Recruitment Flyer (French)



Sujets volontaires requis aux fins d'une étude de recherche sur les expériences des infirmières relatives aux soins aux patients en fin de vie

Objectif de l'étude :

Le but de la présente étude qualitative constituera à accroître nos connaissances sur ce que comporte la prestation de soins en fin de vie au sein d'une unité de médecine et ce qui facilite ou entrave la prestation de ces soins.



Qui peut participer?

- des infirmières et infirmiers autorisés (inf. aut.) qui travaillent au 5 Nord-Est ou au 5 Nord-Ouest pour une durée minimale de 6 mois
- qui sont à l'aise pour communiquer en anglais
- et qui ont de l'expérience avec la prestation de soins aux patients en phase terminale au sein d'une unité de médecine

Cette étude est réalisée par Irene Oliveira, infirmière autorisée et étudiante à la Maîtrise en sciences infirmières à l'Université d'Ottawa, sous la supervision de Frances Fothergill Bourbonnais, Ph.D. professeure émérite à l'École des sciences infirmières.

Que comporte la participation?

Vous serez invité à participer à deux entrevues avec la chercheuse Irene Oliveira : la première durera de 30 à 60 minutes et la seconde sera d'environ 20 minutes. Ces entretiens auront lieu en dehors de vos heures de travail, et à un endroit qui vous conviendra. Les entrevues seront enregistrées.

Si vous souhaitez participer, veuillez communiquer avec Irene Oliveira pour obtenir de plus amples renseignements.

Votre participation à cette recherche peut contribuer à accroître nos connaissances relatives à la prestation de soins en fin de vie au sein d'unités médicales. Cette étude a été approuvée par le Conseil d'éthique en recherches de L'Hôpital d'Ottawa.

Appendix C: Combined Information Sheet/Consent Form (English)



The Lived Experience of Nurses Providing End-of-Life Care to Patients on an Acute Care Medicine Unit

Principal Investigator:
Irene Oliveira, RN, B.Sc.N.
M.Sc.N. Student,
University of Ottawa, Faculty of Health Sciences
School of Nursing

Co-Investigator:
Dr. Frances Fothergill Bourbonnais, RN., Ph.D.
Professor Emeritus,
University of Ottawa, Faculty of Health Sciences
School of Nursing

Introduction

You are being asked to participate in this study because you are a nurse who has experienced looking after patients who are dying on a medicine unit. Please read this information sheet and consent form carefully and ask as many questions as you like before deciding whether to participate.

Study Purpose

Little is known about what it means to provide nursing care to a patient who is dying on a medicine unit from the perspective of the nurse. The purpose of this qualitative study is to explore what it is like for nurses to provide end-of-life care on a medicine unit and what helps or hinders the provision of this care.

Study Procedure

Your participation in this study will consist of two face-to-face interviews with the Principal Investigator which will be audio-recorded in order to maintain an accurate record of the information you have shared. These interviews will take place at a time, outside of your working hours, and a location convenient to you. They will be conducted in English, so you must be comfortable communicating in English in order to participate.

The first interview will be 30-60 minutes in length. During the interview, you will be asked to describe, in as much detail as you feel comfortable, your experience caring for patients dying on your medicine unit. You may choose not to answer any questions or end the interview at any time. You will also be asked some background questions about yourself such as: your age, education

level, years of nursing experience, years of nursing experience in medicine, and years of employment on your current unit.

The second interview will take place about two months later and will last about 15-20 minutes. In this second interview you will be asked to review the results of the study and you will be given the opportunity to offer feedback on how closely the findings reflect your experience. The second interview will mark the end of your participation in the study.

Risks of Participation

Participation in this study will require that you recall and describe your experiences caring for dying patients which may cause you to feel distress. Every effort will be made to minimize these risks which include stopping the interview at any time you feel distressed or tired. Interviews may be restarted or rescheduled at your convenience. If you choose to no longer participate in this study, all of your information (consent, demographic data and interview record) will be omitted from the study and destroyed.

If at any point during the study you would like to talk to a counsellor, you may access the Ottawa Hospital's employee assistance program provided through Homewood Human Solutions by telephone or online. Counselling services by telephone are available 24 hours a day, seven days a week.

Benefits of Participation

You will not benefit directly from participating in this study. The information you provide will be very important for understanding and guiding supports for nurses caring for dying patients in similar medicine environments.

Compensation

You will not be paid to participate in this research study.

Withdrawal from the Study

You have the right to withdraw from the study at any time without any impact to your current and future employment at The Ottawa Hospital. If you decide to withdraw, please inform the Principal Investigator using the contact information provided on page 1.

Confidentiality

All personal information will be kept confidential, unless release is required by law. The Ottawa Hospital Research Ethics Board and the Ottawa Hospital Research Institute may review relevant study records for audit purposes under the supervision of the investigator. All of the information that you share will be held in confidence and will not be shared with anyone else outside the research team.

You will not be identifiable in any publications or presentations resulting from this study. Verbatim quotes collected during the interview may be included in publications and/or presentations; however identifying information will be omitted.

The consent form you will be required to sign will be stored separately from the responses you give and stored in the office of Dr. Fothergill Bourbonnais. All information which leaves the hospital will be coded with a false name which you will choose at the time of the interview. All audio-recorded data will be transcribed within 48 hours of the interview and then will be deleted. No identifying names will appear on your interview transcripts. Transcribed interview reports will be stored electronically.

The link between your name and the false name assigned to your transcribed interview reports will only be accessible by Ms. Oliveira and Dr. Fothergill Bourbonnais. The link and study files will be stored separately and securely. All paper records will be stored in the security protected office of Dr. Fothergill Bourbonnais, in a locked file, at the University of Ottawa. All electronic records will be stored on a USB key which will be encrypted and will only be accessible to Ms. Oliveira and Dr. Fothergill Bourbonnais

Conservation of data

All files will be kept for a period of 10 years after the study has been completed. At the end of the retention period, all paper records will be disposed of in confidential waste and shredded and all electronic records will be deleted.

Voluntary Participation

Participation is voluntary and you are under no obligation to participate. Your decision to participate or not will have no impact to your current or future employment at The Ottawa Hospital.

Questions about the Study

If you have any questions about this study, please contact Irene Oliveira.

The Ottawa Hospital Research Ethics Board (OHREB) has reviewed this protocol. The OHREB considers the ethical aspects of all research studies involving human participants at The Ottawa Hospital. If you have any questions about your rights as a research participant, you may contact the Chairperson of the OHREB.



The Lived Experience of Nurses Providing End-of-Life Care to Patients on an Acute Care Medicine Unit

Consent to Participate in Research

I understand that I am being asked to participate in a research study about my experience caring for patients dying on an acute care medicine unit. This study has been explained to me by Irene Oliveira, R.N., B.Sc.N., M.Sc.N. student.

I have read this four page Information Sheet and Consent Form (or have had the document read to me). All of my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study. A copy of the signed Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to the Good Clinical Practice Guidelines and Regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

Appendix D: Combined Information Sheet/Consent Form (French)



Feuille de renseignements et formulaire de consentement

Les expériences d'infirmières dispensant des soins terminaux à des patients au sein d'une unité de médecine de soins actifs

Chercheuse principale :

Irene Oliveira, inf. aut., B.Sc.inf.

Étudiante en M.Sc.inf.

Université d'Ottawa, Faculté des sciences de la santé

École des sciences infirmières

Co-chercheuse :

Frances Fothergill Bourbonnais, inf. aut., Ph.D.

Professeure émérite,

Université d'Ottawa, Faculté des sciences de la santé

École des sciences infirmières

Introduction

Vous êtes invité à participer à cette étude parce que vous êtes une infirmière qui a vécu l'expérience de s'occuper de patients mourants au sein d'une unité de médecine. Veuillez lire cette fiche de renseignements et le formulaire de consentement attentivement et poser autant de questions que vous le souhaitez avant de décider de participer ou non.

L'objet de l'étude

Nous en savons très peu sur ce que comporte la prestation de soins à un patient mourant au sein d'une unité de médecine du point de vue de l'infirmière. Le but de la présente étude qualitative est d'explorer ce que signifie pour les infirmières la prestation de soins de fin de vie au sein d'une unité de médecine et ce qui facilite ou entrave la prestation de ces soins.

Méthodologie de l'étude

Votre participation à cette étude se composera de deux entrevues en face à face avec la chercheuse principale. Ces entrevues seront enregistrées sur bandes audio afin de maintenir un registre précis des informations que vous avez partagées. Ces entretiens auront lieu en dehors de vos heures de travail et dans un endroit qui vous conviendra. Elles s'effectueront en anglais, et vous devez donc être à l'aise pour communiquer en anglais afin de prendre part à cette étude.

La première entrevue durera de 30 à 60 minutes. Au cours de l'entrevue, on vous demandera de décrire, avec autant de détails que possible, quelques-unes des expériences que vous avez connues relatives à la prestation de soins à des patients mourants au sein de votre unité de

médecine. Vous pouvez choisir de ne pas répondre à ces questions ou de mettre fin à l'entrevue à n'importe quel moment. On vous posera également quelques questions générales sur vous-même tels que : votre âge, niveau d'éducation, nombre d'années d'expérience en soins infirmiers, nombre d'années d'expérience en soins infirmiers en médecine, et nombre d'années de travail au sein de votre unité actuelle.

La deuxième entrevue aura lieu environ deux mois plus tard et durera environ 15 à 20 minutes. Lors de cette seconde entrevue, on vous demandera d'examiner les résultats de l'étude et vous aurez l'occasion de formuler des commentaires sur la façon dont les résultats reflètent étroitement votre expérience. La deuxième entrevue marquera la fin de votre participation à l'étude.

Risques relatifs à la participation à l'étude

La participation à cette étude nécessitera que vous vous souveniez et que vous décriviez vos expériences dans la prestation de soins à des patients mourants, ce qui pourrait vous causer de la détresse. Nous prendrons toutes les mesures nécessaires afin de minimiser ces risques, y compris la possibilité de mettre fin à l'entrevue à n'importe quel moment où vous ressentirez de la détresse ou de la fatigue. Nous pourrions reprendre ou reporter l'entrevue à un moment qui vous conviendra. Si vous choisissez de ne plus participer à cette étude, on omettra et détruira l'ensemble des informations que vous avez fourni (le consentement, les données démographiques et l'enregistrement de l'entretien).

Si à n'importe quel moment au cours de l'étude vous souhaitez parler à un conseiller, vous pouvez accéder au programme d'assistance aux employés de L'Hôpital, offert par Homewood Solutions Humaines, soit par téléphone ou en ligne. Les services de counseling par téléphone sont disponibles 24 heures par jour, sept jours par semaine.

Bienfaits relatifs à la participation à l'étude

Vous ne bénéficierez pas directement de votre participation à cette étude. Les informations que vous allez fournir s'avéreront très importantes pour comprendre et orienter le soutien aux infirmières qui s'occupent de patients mourants dans des environnements médicaux similaires.

Rémunération

Vous ne serez pas rémunéré pour participer à cette étude de recherche.

Retrait de l'étude

Vous avez le droit de vous retirer de l'étude à tout moment sans que votre décision n'influe sur votre emploi actuel et futur à L'Hôpital d'Ottawa. Si vous décidez de vous retirer, veuillez en informer la chercheuse principale en communiquant avec cette dernière aux coordonnées qui figurent à la première page.

Confidentialité

Tous les renseignements personnels demeureront confidentiels, à moins que leur divulgation ne soit exigée par la loi. Des représentants du Conseil d'éthique en recherches de L'Hôpital d'Ottawa, ainsi que de l'Institut de recherche de l'Hôpital d'Ottawa, peuvent revoir vos dossiers pertinents de l'étude sous la supervision de la chercheuse, uniquement à des fins de vérification. Toutes les informations que vous partagez demeureront confidentielles et ne seront transmises à personne en dehors de l'équipe de recherche.

Aucune publication ou présentation résultant de cette étude ne pourra servir à vous identifier. Des citations textuelles recueillies dans le cadre de l'entrevue peuvent être incluses dans les publications ou les présentations toutefois, aucune information pouvant servir à vous identifier ne fera partie de ces dernières.

Le formulaire de consentement que l'on vous demandera de signer sera stocké séparément des réponses que vous fournirez et sera conservé dans le bureau de la D^{re} Fothergill Bourbonnais. Toutes les informations qui seront transmises à l'extérieur l'hôpital seront codées d'un faux nom que vous choisirez au moment de l'entrevue. Toutes les données audio enregistrées seront transcrites dans les 48 heures suivant l'entrevue, puis seront ensuite supprimées. Aucun nom pouvant servir à vous identifier n'apparaîtra sur votre relevé de notes d'entrevue. Les rapports d'entrevue transcrits seront stockés électroniquement.

Le lien entre votre nom et le faux nom attribué à vos rapports d'entrevue transcrits ne sera accessible qu'à Mme Oliveira et D^{re} Fothergill Bourbonnais. Le lien et les fichiers d'étude seront sauvegardés séparément et en lieu sûr. Tous les documents papier seront sauvegardés dans le bureau sécurisé de la D^{re} Fothergill Bourbonnais, dans un classeur verrouillé, à l'Université d'Ottawa. Tous les dossiers électroniques seront sauvegardés sur une clef USB codée et ne seront accessibles qu'à Mme Oliveira et D^{re} Fothergill Bourbonnais.

Conservation des données

Tous les fichiers seront conservés pour une période de 10 ans suivant la fin de l'étude. À la fin de la période de rétention, tous les dossiers papier seront jetés aux rebuts confidentiels et déchiquetés et tous les dossiers électroniques seront supprimés.

Participation volontaire

La participation est volontaire et vous n'êtes sous aucune obligation d'y participer. Votre décision de participer ou non à cette étude n'aura aucune incidence sur votre emploi actuel ou futur à L'Hôpital d'Ottawa.

Questions au sujet l'étude

Si vous avez des questions au sujet de cette étude, veuillez communiquer avec Irene Oliveira.

Le Conseil d'éthique en recherches de L'Hôpital d'Ottawa (CÉRHO) a révisé le présent protocole. Le CÉRHO est chargé de l'ensemble des aspects éthiques de toutes les études de recherche portant sur des participants humains effectuées à L'Hôpital d'Ottawa. Pour toute question au sujet de vos droits à titre de participant de recherche, veuillez communiquer avec le président du CÉRHO.



Les expériences d'infirmières dispensant des soins terminaux à des patients au sein d'une unité de médecine de soins actifs

Consentement à participer à la recherche

Je reconnais que l'on sollicite ma participation à une étude sur ce que comporte la prestation de soins terminaux à des patients mourants au sein d'une unité de médecine de soins actifs. Irene Oliveira, inf. aut., B.Sc.inf, étudiante, M.Sc.inf., m'a fourni les renseignements nécessaires au sujet de cette étude.

J'ai pris connaissance des quatre pages de cette Feuille de renseignements et de ce Formulaire de consentement. On a répondu à toutes mes questions de manière satisfaisante. Si je décide plus tard au cours de l'étude de retirer mon consentement, il me sera possible de faire en tout temps.

J'accepte volontairement de participer à cette étude. On me remettra une copie signée du formulaire de consentement.

Signatures

Nom du participant (en caractères d'imprimerie)

Signature du participant

Date

Énoncé du chercheur (ou de la personne chargée d'obtenir le consentement)

J'ai expliqué soigneusement au participant de la recherche la nature de l'étude susmentionnée. Pour autant que je sache, le participant apposant sa signature à ce consentement reconnaît la nature, les exigences, les risques et les avantages que comporte sa participation à l'étude. Je reconnais ma responsabilité envers le soin et le bien-être du participant susmentionné, le respect des droits et des désirs de ce dernier, et le déroulement de cette étude, conformément aux directives et aux règlements relatifs à la bonne pratique clinique.

Nom du chercheur/délégué (en caractères d'imprimerie)

Signature du chercheur/délégué

Date

Appendix E: Demographic Form**The Lived Experience of Nurses Providing End-of-Life Care to Patients on an Acute Care
Medicine Unit: Participant Demographics**

Participant self-assigned study name _____

1. What is your age? _____
2. What is your highest education level achieved in nursing? _____
3. What is your total years of nursing experience? _____
4. What is your total years of nursing experience in medicine? _____
5. How long have you been employed on your current unit? _____
6. Have you taken any palliative care courses _____, if yes, approximately how long ago? _____

Appendix F: Interview Guide

1. Can you tell me what it is like for you to care for a patient who is dying on your unit?
2. What are some of the things that make it easier for you to care for dying patients?
3. What are some of the things that make it more difficult for you to care for dying patients?
4. How do you feel when you are looking after dying patients on your unit?