

AN INTERPRETIVE DESCRIPTION OF NURSES' EXPERIENCES OF PATIENTS'
DEATHS IN COMPLEX CONTINUING CARE

AN INTERPRETIVE DESCRIPTION OF NURSES' EXPERIENCES OF PATIENTS'
DEATHS IN COMPLEX CONTINUING CARE

By

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LAY ABSTRACT

Complex continuing care (CCC) is a healthcare setting where many people die. Patient deaths can be difficult and sad for nurses. The goal of this study was to learn more about nurses' experiences when patients die in CCC. Nurses were asked to share memories of when patients died in CCC. This study found that patient deaths influence nurses personally and professionally. Nurses with fewer death experiences were uncomfortable caring for dying patients. Feeling understood and having their experience recognized were meaningful ways that nurses wanted to be supported. It was very important to nurses that the deceased person was respected and nurses worried about patients' family members. This research shows that nurses with fewer death experiences would benefit from unique education and support. It is important to support nurses by creating a culture that acknowledges death in CCC and nurses' responses to patients' deaths.

ABSTRACT

Complex continuing care (CCC) is a healthcare setting where many patients die. Previous research has demonstrated that patient deaths can be meaningful and challenging for nurses. However, little knowledge exists regarding how the unique features of CCC influence nurses' experiences in managing patient deaths. The objective of this study was to explore nurses' experiences when patients die and their perceptions of support surrounding these experiences.

Using interpretive description methodology, 13 memorable patient death experiences were explored in semi-structured interviews with licensed nurses (n=12) and nursing leaders (n=1). Criterion and theoretical purposeful sampling were used to develop a rich understanding of nurses' experiences when patients die. Concurrent data collection and analysis uncovered five key intersubjective themes which described nurses' experiences with individual deaths and how nurses' experiences change overtime which included: (a) Professionally experiencing patients' deaths: 'Engaging your left brain;,' (b) Personally experiencing patients' deaths: 'I'm a human being too;,' (c) Seeking resolution in the experience: 'It was a good resolution;,' (d) Integrating professional and personal experiences: 'Applying what you learn in your nursing life into your personal life and vice versa,' and; (e) Supporting One Another in a Culture of Acknowledging Patients' Deaths and Nurses' Experiences: 'They expect us just to take it, the nursing profession is like that.' These findings suggest that nurses need support to facilitate the interpersonal and intrapersonal aspects of their experiences with patient death. This support should be grounded in a unit culture which openly accepts patient death and acknowledges nurses'

experience. Just-in-time education, peer mentorship and targeted support may further facilitate nurses' ability to find resolution when patients die and support their on-going journey towards integrating death experiences in their lives and practice.

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LIST OF ABBREVIATIONS

APN	Advanced Practice Nurse
CCC	Complex Continuing Care
CCR	Comfort Care Rounds
CIT	Critical Incident Technique
EOL	End-of-life
GSF	Gold Standard Framework
HCP	Health care provider
ID	Interpretive Description
IR	Interactive-Relational Approach
MAID	Medical Assistance in Dying
MS	Multiple Sclerosis
RN	Registered Nurse
RPN	Registered Practical Nurse
PSW	Personal Support Worker

DECLARATION OF ACADEMIC ACHIEVEMENT

I, Christy Konietzny, declare that this work is my own and, if not, I have acknowledged the original source using APA or another approved citation format.

Date: July 18, 2016

Graduate Thesis: An interpretive description of nurses' experiences of patients' deaths in complex continuing care

Signature: 

CHAPTER 1

INTRODUCTION

Background

Canadians are living longer with more chronic conditions (Public Health Agency of Canada, 2014). This population trend coupled with greater numbers of children born with disabilities surviving, and higher use of life-sustaining measures contribute to an increasing demand for services such as complex continuing care (CCC) (see Appendix A for Glossary of Terms) (Ontario Hospital Association [OHA] 2006). From 2014 to 2015, 28 of CCC patients died in Ontario and patient death accounted for one third of discharges from this service (Canadian Institute for Health Information [CIHI], 2015). Thus, CCC is a significant setting where people die in Ontario.

Nurses are closely positioned to the patient and family and are therefore critical to the delivery of quality end-of-life (EOL) care in CCC (Registered Nurses' Association of Ontario, 2011). Previous research shows that nurses believe that an important part of their role is facilitating a good death for patients (Borbasi, Wotton, Redden & Chapman, 2005; McNamara, Waddell & Colvin, 1994; Payne, Langley-Evans & Hillier, 1996). In addition, nurses are emotionally impacted by patients' deaths (Anderson, Kent & Owens, 2015; Gerow et al., 2010; Wilson & Kirshbaum, 2011) and experience loss (Gannon & Dowling, 2012, Gerow et al., 2010) and grief (Marcella & Kelley, 2015; Rickerson et al., 2005). These findings are particularly common in continuing care settings such as CCC related to the family-like relationships which can develop over patients' long lengths of stay (Gannon & Dowling, 2012; Munn et al., 2008; Sumaya-Smith, 1995; Wilson &

Daley, 1998). Many studies also found that nurses and other care providers perceive little formal support to assist them in their experiences when patients die (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; Wilson & Daley, 1998).

Nurses' experiences providing care to patients at EOL can be influenced by many attributes of the care setting and patient population, and these include the setting or organizational care philosophies, staff training and knowledge, available support services (Mezey, Dubler, Mitty & Brody, 2002), and the cultural and social environment (Noppe, 2000). Their experiences are also shaped by the length and quality of relationships that they develop with patients (Gannon & Dowling, 2011; Marcella & Kelley, 2015; O'Hara, Harper, Chartrand & Johnston, 1996; Rickerson et al., 2005; Sumaya-Smith, 1995). Further still, individual characteristics of patients and nurses and past experiences with death may alter nurses' subsequent experiences when patients die (Anderson et al., 2015; Gerow et al., 2010; Marcella & Kelley, 2015; Noppe, 2000; O'Hara et al., 1996). The circumstances of the patient's death, whether it is expected or perceived as a 'good' or 'bad' death, can influence nurses' experiences and subsequent response to the death of a patient (Anderson et al., 2015; Costello, 2006; Gerow et al., 2010; Noppe, 2000; Marcella & Kelley, 2015).

CCC is a care setting for patients who no longer require acute care, but whose care needs exceed the capacity of home care or other care settings (CIHI, 2014; Ontario Ministry of Health and Long Term Care, 2010). Patients requiring this service are typically younger and have more complex health needs than residents of long term care (LTC) (CIHI, 2007; McGilton, Robinson, Boscart & Spanjevic, 2006). Other terms for

this service include extended care, continuing care or chronic care (CIHI, 2014). Applied knowledge is required to address the knowledge gap of nurses' experiences when patients die in the unique CCC setting.

Research Purpose

One Canadian survey study found that 42% of nurses and other direct-care providers are negatively affected by patient death in CCC (O'Hara et al., 1996). This demonstrates that CCC is an important clinical setting in which many patients die and nurses are at high risk for having negative experiences. There is currently exists a gap in our understanding of nurses' experiences and support needs when patients die in CCC and the presence and influence of different setting attributes on nurses' experiences. Understanding nurses' experience of patients' deaths in CCC is important because nurses' perceptions of their experiences can subsequently influence the delivery of consistent and quality patient care, (Anderson et al., 2015; Gibson et al., 2008), nurses' job satisfaction, turnover, attrition (Anderson et al., 2015; O'Hara et al., 1996), nurses' health problems and nurses' personal relationships (O'Hara et al., 1996).

The purpose of this study is to explore and develop an understanding of nurses' experiences of patient death in CCC. Exploration of this phenomenon will facilitate the creation of appropriate educational and supportive resources for nurses in order to help them prepare for the inevitable practice experience of patient death. These interventions may reduce the number of negatively perceived experiences that nurses have caring for patients at EOL, support nurses' coping after patients' deaths and may ultimately enhance

nurses' well-being, optimizing the delivery of palliative and EOL care for patients and families in CCC.

Self-Reflection

My interest in nurses' experiences of death in their practice first started in my experiences as a registered nurse (RN) working on medicine and surgical units in a community hospital. My first experience caring for a patient who died occurred only one month after I started working independently. Amidst assessing and administering medication to my other patients, one of my patients quickly declined. His family called for me and had questions about what was happening. I felt completely overwhelmed by all of my simultaneous responsibilities and I did not feel confident explaining what was happening to the family and supporting them as they witnessed their family member dying. Thankfully I worked with a very supportive charge nurse who patiently spoke to the family with me, taught me to pronounce the patient after his death and walked me through the process of charting and after death care. I became very emotional after this experience because I had felt helpless and unprepared to help the family in the moment when they needed my support as a nurse. At the time, this patient's death was my first experience being close to and affected by a person's death.

My interest in nurses' experiences caring for dying patients evolved in my graduate studies, specifically during a clinical placement with an advanced practice nurse in a CCC and rehabilitation hospital. My preceptor shared with me about a quality improvement project she led in which she explored the organization's after-death care policy and efforts made to make it person-centred. She learned through focus groups with

nurses that they experienced significant distress providing this care to a person whom they cared for over many years and with whom they shared a special relationship. I was moved by this work and I reflected on how different nurses' experiences in CCC were from my own after knowing the patient for only a few hours.

Through this placement and part-time work in the CCC care setting, my interest in nurses' experiences of patient death grew, particularly in settings where patients receive care over long periods of time. I was surprised to find very little literature that was set in CCC. Therefore, I saw my graduate thesis work as an opportunity to both explore an area of interest from my practice and to create knowledge to support nurses in CCC.

CHAPTER 2

LITERATURE REVIEW

Search Strategy

A comprehensive literature review was conducted in order to explore existing research relating to nurses' experiences of death in CCC. Databases including the Cumulative Index to Nursing & Allied Health Literature (CINAHL), Ovid MEDLINE (R) In-process and other non-indexed citations, OVID Medline (R) Daily, Ovid MEDLINE (R) 1946- September, 2015, Embase (1974 – September, 2015) and PsychINFO (1987 to September, 2015) were searched. Limits were set to capture English and peer reviewed articles and no date restriction was set to ensure seminal articles were found. Key words pertaining to nurses', patient death, CCC and similar care settings, nurses' experiences, support and nurse-patient relationships were used (see Appendix B).

Articles were removed if the sample did not include nurses, when the setting was other than continuing or acute care, if the articles were editorials or if patient death experiences were isolated to a single condition (e.g. dementia). Studies from acute care were included if they met all criteria because the complexity of patient's care needs in CCC may be more similar to patients in acute care as opposed to LTC. Additional searching included using a 'cited by' function, hand searching reference lists and simplified searches in Google Scholar (e.g. 'patient death' AND 'complex continuing care'). Thus, 23 articles were used to inform this review (see Appendix C for studies reviewed and their research methods). Seven of the 23 articles were critical to the development of knowledge in this review because their findings were richly described

and they employed diverse methods to explore different aspects of nurses' experiences (e.g. loss, grief, support needs), thus contributing to more complete picture of nurses' experiences.

The majority of studies were qualitative research studies (n=18) which used phenomenological philosophy (n=5), literature review or concept analysis (n=3), generic qualitative design (n=8), grounded theory technique (n=1) and ethnographic methods (n=1). Four quantitative studies were captured which employed a questionnaire design. Finally, one theoretical paper presenting a model of health care providers' grief was included (see Appendix C). The retrieved articles were conducted in Canada, the United States of America, the United Kingdom and Europe. Most studies were set in LTC (n=11). An additional five studies occurred in acute care or in multiple care settings. Only one dated study was set in a continuing care hospital (O'Hara et al., 1996). This review elucidated many patient, nurse, relationship and organizational characteristics which can influence nurses' experiences of patient death. These studies also contributed to an understanding of different ways that nurses express or acknowledge their patients' deaths as part of their experience. Finally, nurses' support preferences and needs and individual nurse coping strategies were captured and will be reviewed and synthesized (see Table 1 for literature review overview).

Acknowledging and Experiencing Patients' Deaths

When patients die and following their death, nurses' experiences may encompass how they feel and what they do to recognize the patient and their own experience. The reviewed studies yielded several ways that nurses recognize the patient and their death

and these include; (a) reprioritizing care tasks (Gannon & Dowling, 2011; Marcella & Kelley, 2015; Munn et al., 2008; Wilson & Daley, 1998); (b) remembering the patient (Anderson et al., 2015; Gerow et al., 2010; Gannon & Dowling, 2011; Marcella & Kelley, 2015; Munn et al., 2008; Papatadou, 2000; Wilson & Daley, 1998); (c) participating in ceremonies or rituals (Gannon & Dowling, 2011; Gerow et al., 2010; Maitland et al., 2012; Papatadou, 2000; Wilson & Daley, 1998); and (d) nurses' emotional experience when patients die (Gannon & Dowling, 2011; Gerow et al., 2010; Maitland et al., 2012; Marcella & Kelley, 2015; Papatadou, 2000; Rickerson et al., 2005; Sumaya-Smith, 1995; Wilson, 2014).

Reprioritizing Care

Leading up to a patient's death, nurses and other direct care providers prioritized the care of dying patients and ensured that the patient was not alone. Wilson and Daley (1998) found that nurses placed dying patients' care needs before other patients. Nurses in this study spent any extra time available with the dying individual. They expressed a sense of duty in several studies to ensure that a dying patient did not die alone (Gannon & Dowling, 2011; Marcella & Kelley, 2015; Munn et al., 2008; Wilson & Daley, 1998). These findings show that nurses acknowledge the importance of the dying process by reorganizing their care and finding extra time to spend with their patient.

Remembering and Reminiscing

Several studies found that patients' deaths were often memorable to nurses and health care providers (HCP) (Anderson et al., 2015; Gannon & Dowling, 2011; Gerow et al., 2010). Anderson and colleagues (2015) found that details of some patient deaths

could be recalled decades after the event, and still evoked a strong emotional response as nurses relived the memory. Gannon and Dowling (2011) explain that patients in long term care settings become part of HCPs' lives and thus continue to live on in HCPs' memories after their deaths. A sense of missing the person and continuing to care about them after they died was a common finding (Gannon & Dowling, 2011; Munn et al., 2008; Wilson & Daley, 1998).

Beyond personally reliving memories of deceased patients, nurses and other care providers reminisce with one another, other patients and patients' family members through the sharing of memories and stories about the deceased person (Gannon & Dowling, 2011; Marcella & Kelley, 2015). This social process helped unit staff to find meaning in patients' deaths by weaving memories of the patient into the fabric of the unit (Gannon & Dowling, 2011; Gerow et al., 2010; Papatadou, 2000). Reminiscing about deceased patients may be an important way that nurses process and acknowledge the deaths of patients. It also demonstrates that nurses' experiences are not limited to the period surrounding the person's death.

Ceremonies and Rituals

Maitland and colleagues (2012) explored the value that nine LTC employees found in attending formal room blessing rituals for deceased residents in a Canadian Catholic LTC home. This ritual was attended by staff, residents and family members and was led by spiritual care staff. In the deceased resident's room, memories were shared about the resident and ritual attendees prayed and blessed the room for the in-coming subsequent resident (Maitland et al., 2012). Overall, staff described that they valued the

time and space provided to acknowledge and say goodbye to the resident and this ceremony helped prepare them to care for the new resident. This positive experience created a sense of community as the attendees acknowledged the patient's life and death together (Maitland et al., 2012). Despite a lack of detail provided regarding this study's analysis approach, this study provided a meaningful description of an organizational ritual which acknowledged both the deceased person and the loss experiences of staff, other residents and family members.

Nurses also engaged in personal or formal rituals to acknowledge the life and death of a patient who died. One study found that attending a patient's funeral or memorial service was important to the loss experience of nurses in LTC (Gannon & Dowling, 2011). Papatadou (2000) explains that funerals can symbolize closure of nurses' relationships with patients and their family members. Another study found that organizing a funeral for a patient who had no other family allowed nurses to honour and respect the life of the patient and positively influenced nurses' experience by creating a sense of pride and satisfaction in their work (Gannon & Dowling, 2011).

Other studies described individual nursing rituals embedded in nurses' patient death experiences (Gerow et al., 2010; Wilson & Daley, 1998). Care providers in one study desired to prepare and cleanse the patient's body after death in order to show respect and caring for that person (Wilson & Daley, 1998). Nurses from another study engaged in caring rituals for dying patients that included providing oral care, fresh linens, food, and tissues (Gerow et al., 2010). These actions doubled as coping strategies for nurses by allowing them to show caring while helping them to maintain a sense of control

over aspects of the dying experience (Gerow et al., 2010). Both personal and group ceremonies and rituals contribute positively to nurses' experiences by allowing them to express caring for and recognition of the deceased person.

Nurses' Emotional Experiences When Patients Die

The death of a patient can be very emotional and challenging for nurses (Gannon & Dowling, 2011). One study described different types of emotions and feelings that can accompany a patient's death in LTC and these included pain, loneliness, sadness and feeling emptiness (Gannon & Dowling, 2011). Nurses' experiences and emotions also differed depending on the circumstances of the person's death, such as it being unexpected or dying away from the home in an acute care hospital. These types of death were associated with feelings of helplessness and distress (Gannon & Dowling, 2011).

Many studies specifically explored nurses' experiences of patients' deaths as it related to loss and expressions of bereavement and grief (Gannon & Dowling, 2011; Gerow et al., 2010; Marcella & Kelley, 2015; Rickerson et al., 2005). In one survey study, 72% of LTC employees reported experiencing at least one grief-related symptom (e.g. feeling sad or crying) following a resident's death in the last month (Rickerson et al., 2005). In a second survey study of 25 skilled nursing facility staff, 56% of respondents reported the occurrence of surrogate grieving (Sumaya-Smith, 1995) which results when healthcare providers experience similar feelings of grief as bereaved family members following a patient's death (Fulton, 1987). These studies show that grief is a common reaction to the death of patients in continuing care settings. Experiencing a greater number of grief symptoms was related to having a longer and closer relationship with the

deceased resident (Rickerson et al., 2005). This indicates that nurses may perceive a patient's death as a personal loss and subsequently experience grief (Gannon & Dowling, 2011; Marcella & Kelley, 2015; Rickerson et al., 2005; Sumaya-Smith, 1995).

One conceptual model outlined six potential sources of loss that can lead to grief in health care providers (Papatadou, 2000). They include; (a) loss of a close relationship; (b) identifying with the family's loss; (c) loss of professional expectations, role or image as a care provider; (d) the death may challenge and lead to a loss of the care provider's worldview; (e) a patient's death may trigger past unresolved losses or lead the care provider to anticipate future losses; and (f) the patient's death threatens the care provider's sense of mortality (Papatadou, 2000). Health care providers' grief is complex and it may be important to consider the nature of the perceived loss when providing support to nurses when a patient dies (Papatadou, 2000).

Loss and bereavement in nurses has been described as similar to losing a close family member in several studies (Gannon & Dowling, 2011; Munn et al., 2008; Papatadou, 2000; Sumaya-Smith, 1995). Examples of the most common grief-responses of LTC employees included feelings of sadness, crying and inability to accept a patient's death (Rickerson et al., 2005). Papatadou (2000) described that HCPs may report sorrow, depression, anger or guilt following a patient's death. A sense of relief may also accompany grief because despite loss, they wished for the patient's suffering to end (Papatadou, 2000). However, grief may be expressed in unique ways by each person, as influenced by personal experience, culture and organizational factors (Marcella & Kelley, 2015; Papatadou, 2000). Marcella and Kelley (2015) described the burden of grief for

nurses' and care providers in LTC is compounded due to the frequency of residents' deaths. Because of this, the emotion of grief is on-going, unrelieved and entrenched in their work (Marcella & Kelley, 2015).

An internal conflict may arise when nurses perceive that the emotion and expression of grief are unprofessional responses to the death of a patient (Gerow et al., 2010). Some nurses perceived that they were not supposed to or permitted to feel grief and expectations that they must move on to the next patient (Gerow et al., 2010). As such, nurses are hesitant to speak openly and discuss how patient death affects them (Marcella & Kelley, 2015; O'Hara et al., 1996; Wilson, 2014). An awareness of barriers to nurses' expression of grief or other negative responses to patient death is important when conducting research about this phenomenon. Nurses may experience additional loss when relationships with patients' family members end abruptly following the death of a patient (Maitland et al., 2012; Marcella & Kelley, 2015). This experience of multiple losses may compound nurses' experiences of patient death.

In summary, nurses acknowledge patients' deaths by reprioritizing care, remembering and reminiscing and ceremonies and rituals and through emotional expressions of loss and grief. These expressions may be personal to each nurse and occur at a unit or organizational level. Health care leaders should develop an awareness of the nurses' emotions and preferences for acknowledging patients when they die when developing and providing support for nurses.

Factors Influencing Patient Death Experience

When attempting to develop an understanding of nurses' experiences of the phenomenon of patient death, it is important to explore the multiple factors which may influence or interact to modify this experience (Mezey et al., 2002; Marcella & Kelley, 2015). Factors which emerged from this literature review included; (a) organizational and care setting attributes; (b) nurse-related factors' (c) characteristics of patients; and (d) elements of the nurse-patient relationship.

Organizational and Care Setting Attributes

The type of care setting directly who provides care to patients, the type and proficiency of skills that they employ and the care philosophy that guides their practice. It also influences care providers' expectations about their work and the relationships that they develop with their patients (Mezey et al., 2002). The influence of the clinical setting on nurses' experiences was supported by several studies in this review (Copp & Dunn, 1993; Gerow et al., 2010; Maitland, Brazil & James-Abra, 2012; Marcella & Kelley, 2015; Munn et al., 2008). Beyond more obvious differences between settings such as funding and staffing, the influence of philosophy of care and setting culture played a part and will be explored in the following sections.

Philosophy of care.

In an older study, the setting philosophy of care was suggested as an explanation of the finding that acute care nurses experienced more problems than hospice and community nurses when caring for dying patients (Copp & Dunn, 1993). Expectations of the public and patients' family members and regulatory requirements of the setting may

also be shaped by the care philosophy (Wilson & Daley, 1998). There is more widespread acknowledgement and understanding by LTC staff, residents and society that LTC will be the final home of the resident (Maitland et al., 2012; Munn et al., 2008). On the other hand, CCC is emphasized as a transitional setting (CIHI, 2006). This philosophy may not adequately reflect the death rate in CCC and could foreshadow that nurses in this setting will be less prepared by the organization for the occurrence of patient death.

Organizational culture.

Other aspects of the care setting or organizational culture such as language used and modes of communicating to staff about patient deaths can influence nurses' perceptions of their experiences (Marcella & Kelley, 2015). An important contribution to the literature was made by this recent Canadian study in LTC, which sought to explore direct care providers' grief and bereavement experiences and to identify their grief support needs. In interviews with a diverse sample of registered nurses (RN), registered practical nurses (RPN) and personal support workers (PSW) from two LTC homes, it was learned that the organizational context and work environment play an important role in care providers' experiences of grief (Marcella & Kelley, 2015). Despite the frequency of residents' deaths in LTC, death was hidden and rarely spoken about in the homes, care staff were not trained or prepared for loss or grieving in the organizational orientation and the participants felt they did not have the required resources to meet the expectation of emotionally supporting residents and family members. Care providers learned 'on the job' from other staff members the unwritten rules of caring for dying patients (Marcella & Kelley, 2015). As a result, these findings had practice implications which together

reflected the need for a care culture which acknowledges death in the care setting and its potential impact on staff.

A lack of openness about death within an organization can imply that death is ‘just part of the job,’ and can be related to care staff feeling that they are not supposed to feel upset when a patient dies (Gerow et al., 2010; Marcella & Kelley, 2015). The influence of the culture and ethos of care in CCC is unknown and has potential to greatly affect nurses’ experiences of patient death.

Nurse-Related Factors

Several characteristics of nurses and their past experiences were found across the reviewed studies to shape nurses’ experiences when patients died. Years of experience (Gannon & Dowling, 2011; Marcella & Kelley, 2015; O’Hara et al., 1996; Rickerson et al., 2005), past experiences with death (Anderson et al., 2015; Gerow et al., 2010; O’Hara et al., 1996; Marcella & Kelley, 2015), nurses’ approaches to their practice and patient relationships (O’Hara et al., 1996; Wilson & Daley, 1998), and nurses’ perceptions of death quality (Anderson et al., 2015; Gerow et al., 2010; Hopkinson & Hallet, 2002; Hopkinson, Hallet & Luker, 2005; Kehl, 2006; Marcella & Kelley, 2015) added to the complex interplay of factors influencing nurses’ experiences and are synthesized in the following sections.

Years of experience.

Two survey studies found that nurses’ who practiced for more years were significantly more likely to have challenging or grief-laden experiences with patient death (O’Hara et al., 1996; Rickerson et al., 2005). These interesting findings threaten the

conception that with more experience, nurses learn to cope more effectively with patient death in their practice. In addition, this suggests nurses' responses to frequent patient deaths can accumulate over time and contribute to negative experiences (Rickerson et al., 2005). Unfortunately, a limitation of survey research is that structured questions do not allow exploration of these findings with study participants to understand their perceptions of how and why this occurs and what other factors are related to their experience of negativity or grief. Despite this, two qualitative studies reported that nurses and direct care providers feel they never adjust to having patients die, even in settings where death is common and expected (Gannon & Dowling, 2011; Marcella & Kelley, 2015). Therefore, years of experience may not support better coping in nurses, and is in fact related to nurses reporting more signs of grief and being more negatively affected when patients die (Rickerson et al., 2005; O'Hara et al., 1996). The high rate of patient death in CCC may put nurses in this setting at greater risk of negative practice experiences with patient death.

Nurses' past experiences with death.

Similarly, nurses' earliest experiences with the deaths of patients are formative and continue to influence their subsequent experiences (Anderson et al., 2015; Gerow et al., 2010; Marcella & Kelley, 2015). A recent qualitative study conducted in New Zealand explored early patient death experiences of nurses from a range of care settings guided by interpretive phenomenologic analysis (Anderson et al., 2015). They found that early death experiences can be vividly recalled and can have a significant and lasting influence on nurses' on-going death experiences, even decades later. Nurses' early

experiences were found to influence their career decisions. For example, some nurses who had positive early patient death experiences sought future careers in palliative care as opposed to some nurses with negative experiences, who avoided clinical settings where dying and death were more common. In future experiences caring for dying patients, early negative experiences were related to emotional distress and positive experiences were associated with increased self-efficacy (Anderson et al., 2015).

Similar results were found in Gerow's and her colleagues' (2010) study which also used a phenomenological approach, this time to explore nurses' lived experiences of patients' deaths and the meaning of these experiences. One of the key themes from interviews with 11 RNs in this rigorous study was that early practice experiences with death are formative for nurses. Nurses who felt supported during early experiences and perceived it as positive overall tended to have better coping and less emotional distress with subsequent patients' deaths (Gerow et al., 2010). Negative early experiences were perceived as traumatic by nurses and contributed to feelings of helplessness in subsequent experiences (Gerow et al., 2010). A limitation of both articles was insufficient description of their sampling strategies, which suggested a reliance on convenience sampling. More strategic and purposefully sampled participants may have led to richer data (Patton, 2015).

In addition to past experiences with death in nurses' practice, having recent personal losses was associated with direct care providers having more negative experiences when patients die in a CCC hospital (O'Hara et al., 1996). It is therefore valuable to explore nurses' past death experiences as it may provide a deeper

understanding of their support needs in future experiences. These findings also imply that early education and appropriate support for novice nurses may lay a foundation for more positive experiences in their future practice.

Nursing approach.

One survey study used the Impact of Patient Death Questionnaire to measure the effect of patient death on nursing staff in a Canadian CCC and rehabilitation hospital (O'Hara et al., 1996). A convenience sample of 126 RNs, RPNs and PSWs completed the survey (response rate 33%). A logistic regression analysis revealed that taking work stress home, struggling to provide care for younger patients, prioritizing the one-on-one relationship with patients as the most important aspect of nursing practice and feeling less acknowledged by their colleagues predicted care providers who were more negatively affected by patients' deaths (O'Hara et al., 1996). This combination of elements suggests a highly involved nursing approach to patient relationships and sensitivity that could place some nurses at greater risk for negative complications following patients' deaths and that targeted and additional support may be required for nurses with these qualities (O'Hara et al., 1996). Although this research highlights the importance of exploring nurses' experiences in CCC, a major limitation of this study is that it did not report the psychometric properties of the survey used nor describe a power analysis to estimate the sample size. Finally, the age of this study limits the transferability of the findings since the provision of nursing care, patient population and organization of CCC services may have changed and with it, the effect on nurses of patients' deaths.

Nurses' perceptions of death quality.

Aspects of patients' death and nurses' subsequent perceptions of the quality of the death add to the complexity of nurses' experiences. A concept analysis of 'good death' found that perceptions of patients' deaths as 'good' or 'bad' are individual, dynamic and related to nurses' past experiences (Kehl, 2006). Although several common antecedents to 'good' death perceptions emerged, it appears that it is the perception itself which influences nurses' experiences (Kehl, 2006). For example, perceptions of a 'good' or positive death experience led to a feelings of satisfaction in nurses (Anderson et al., 2015; Gerow et al., 2010; Marcella & Kelley, 2015). Nurses felt a sense of pride and pleasure in their work when they were able to contribute to a 'good' death for a patient (Anderson et al., 2015). Nurses were more accepting of a patient's death when they perceived it as 'good' and this was comforting to nurses (Marcella & Kelley, 2015). From an ethnographic perspective, Costello (2006) found that good deaths facilitated nurses' ability to maintain a sense of control over their practice.

Negative perceptions of death quality or perceptions that it was a 'bad' death contributed to negative outcomes for nurses in different studies. Low morale was found in two studies (Costello, 2006; O'Hara et al., 1996). A perceived bad death in an acute care setting was described as leading to conflict among nursing and medical staff (Costello, 2006). A bad death and its outcomes of low morale and conflict created a sense of trauma for nurses in one study (Costello, 2006). In LTC, bad quality of death of patients contributed to a sense of moral distress or angst among nurses (Marcella & Kelley, 2015). Gibson and colleagues (2008) identified that varying perceptions of death quality can

subsequently impact the delivery of consistent and quality patient care. Therefore, it is important to consider nurses' perceptions of death quality when exploring nurses' experiences and when developing and strengthening support for nurses in CCC (Flanagan, 1954; Janes, Fox, Lowe, McGilton & Schindel-Martin., 2009; Kehl, 2006; Kemppainen, O'Brien & Corpuz, 1998).

Patient Characteristics

Characteristics of the patient were discussed as being important to nurses' experiences, however were rarely a key finding in the reviewed studies (Mezey et al., 2002; Noppe, 2000). Evidence from one survey study in CCC suggests that nurses are more negatively affected by a patient's death when the patient is young (O'Hara et al., 1996). Since half of the studies were conducted in LTC, this was less likely to emerge in the reviewed studies related to the aged population. However, 20% of patients are younger than 65 years old in CCC and this factor may be found to be more important in this clinical setting (CIHI, 2007). Four studies found that reciprocity from patients was engaging to nurses and led to closer relationships (Gannon & Dowling, 2011; Gerow et al., 2010; McGilton & Boscart, 2007; Munn et al., 2008). The mutual sharing between nurses and patients about their lives contributed to a sense of togetherness and supported close care provider-patient relationships (McGilton & Boscart, 2007). Patients' cognitive capacity, communication skills and social interaction skills were important facilitators of their ability to engage with and demonstrate caring reciprocity to nurses (McGilton & Boscart, 2007). Characteristics of the patient such as age, background or life circumstances may support the nurse to identify more with the patient, thus changing the

nature of their relationship and the nurses' experience when the patient dies (Gerow et al., 2010).

The Nurse-Patient Relationship

There is a “complex multi-person and interdependent network of relationships around each dying person” (Hopkinson et al., 2005, p. 128). Five studies found that nurses believed that knowing the resident personally and forming attachments with them was critical to providing quality EOL care in LTC settings (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; O'Hara et al., 1996; Wilson & Daley, 1998). In addition, these relationships bring satisfaction and quality to care providers' work lives (Katz et al., 2001; Sumaya-Smith, 1995). Factors which contribute to the development of close relationships and the relationship's influence on nurses' experiences will now be explored.

Time and physical closeness.

In a large, multi-site American study, which sought to examine the EOL experience of residents, families and staff in LTC, key findings from focus groups with licenced nurses and PSWs revealed that the care provider-resident relationship is critical to the delivery of EOL care and that blurring of relationship boundaries between patients and families leading to family-like relationships (Munn et al., 2008). Physical proximity, frequency and regularity of contact of staff with residents and families interpreted as *closeness* emerged as the central category in the study's use of grounded theory technique, which connected and influenced the main themes (Munn et al., 2008). These findings are relevant to the care context of CCC however it was not clear and rationale

was not provided as to why a grounded theory approach to data analysis was used. A further concern was that residents and family members were directly approached by the research coordinator introducing concerns over how participants' well-being was protected during recruitment.

The high level of physical and social contact between care providers and clients in continuing care settings (Marcella & Kelley, 2015) can support the development of close relationships and attachments over months and years (Gannon & Dowling, 2011; McGilton & Boscart, 2007). Time is a key ingredient to knowing the patient well (Gannon & Dowling, 2011; Zolnierek, 2014). The regularity, consistency and frequency of contact with patients during this time influence not only the nurses 'knowing the patient' (Zolnierek, 2014) but also influences the mutual closeness of their relationship (Munn et al., 2008).

Over longer periods of time, the nurse-patient relationship may move towards a personal or family-like relationship (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; Munn et al., 2008; Sumaya-Smith, 1995; Waldrop & Nyquist, 2011; Wilson & Daley, 1998). Longer relationships with patients who died were significantly associated with reporting higher amounts of grief-related symptoms such as feeling helpless or being unable to accept the patient's death by a large sample of inter- and paraprofessional staff in LTC (Rickerson et al., 2005). Longer and closer nurse-patient relationships contribute to perceptions of the patient's death as personal loss for nurses and experiences of grief (Munn et al., 2008). With an average length of stay from 88 to 160 days in CCC, and some patients' stays far exceeding 180 days (CIHI, 2007),

there is more time for nurses to develop close relationships with their patients. Therefore, nurses who work in CCC are at risk of experiencing grief in response to their patients' deaths because of the length and intimacy of their relationships with patients.

Attachment and family-like relationships.

A large study of 155 licensed nurses, PSWs and administrative staff from 11 LTC homes described staff's perspectives of death and dying in LTC and barriers to providing quality care to residents at EOL (Wilson & Daley, 1998). Attachment to residents was viewed as essential to providing quality EOLC care and improved the care providers' experiences and was associated with positive EOL outcomes and closure. Attachment was influenced by factors of the home (time, space & spiritual care), factors of the care provider (caring, presence, communication and knowledge) and external factors (patient population, expectations from family and regulatory requirements). This study contributed a valuable and comprehensive understanding of the complex interrelationships of factors influencing nurses' experiences in LTC and was unique because it included administrators. However, the article itself did not provide sufficient information about data analysis or methods used to enhance study rigour therefore it is difficult to evaluate the trustworthiness of the findings.

In a more recent study, Gannon and Dowling (2011) explored nurses' experiences of loss with seven nurses working in a residential LTC home in Ireland. In semi-structured interviews and rigorous interpretive phenomenological analysis it was found that knowing the patient well and creating a sense of belonging was an important part of quality care delivery. A 'ward family' resulted from caring for residents as people in their

own home, and included residents, staff and the residents' family members. Because of the close bonds that developed among members of the ward family, a resident's death was a considerable loss felt by nurses (Gannon & Dowling, 2011). The small study sample from one research setting in Ireland may reduce the transferability of results.

Other studies have described similar findings in LTC, such as Marcella and Kelley's (2015) description of the dual responsibility of direct care providers to attach to residents to provide good EOL care and then learn to detach after their death to continue their work with other residents. Three additional studies described nurses' emphasis on knowing the patient well and developing attachments to provide quality EOL care (Katz et al., 2001; Marcella & Kelley, 2015; O'Hara et al., 1996). Developing family-like relationships or caring for residents as if they were family members was also commonly described (Katz et al., 2001; Gannon & Dowling, 2011; Munn et al., 2008; Sumaya-Smith, 1995; Waldrop & Nyquist, 2011; Wilson & Daley, 1998). Munn and colleagues (2008) described this as a blurring of boundaries which contributed to a family-like bereavement for the participants. Another study described how nurse-patient relationships surrounding EOL transcend traditional professional boundaries and are reciprocal in nature (Gerow et al., 2010).

In one skilled nursing facility, 92% of staff reported having a surrogate-family bond with patients and half of this sample felt a family-like bond with over ten patients at one time (Sumaya-Smith, 1995). A familial closeness may also develop between nurses and residents' family members (Sumaya-Smith, 1995; Maitland et al., 2012). Nurses feel a sense of familial duty when the patient or resident has no other family. In these

instances, nurses coordinate and alter their practice routines to ensure that this person is not left alone when they are dying (Gannon & Dowling, 2011; Marcella & Kelley, 2015; Munn et al., 2008; Wilson & Daley, 1998). Circumstances in which nurses became ‘replacement family’ were found to be more memorable and sad for care providers following the patient’s death (Gannon & Dowling, 2011).

Continuing care settings such as CCC provide a milieu in which nurses are likely to feel connected to and attached to their patients. They may connect to long-stay patients like family members and therefore feel the death as a personal loss (Gannon & Dowling, 2011; Gerow et al., 2010) or an experience of grief (Gerow et al., 2010; Marcella & Kelley, 2015; Rickerson et al., 2005; Sumaya-Smith, 1995). It is important that organizations recognize the potential for nurses’ experiences to resemble family-like grief and consider this when developing and providing education and support for their staff.

In summary, this review identified many pertinent factors which influence nurses’ experiences of patient death. These factors were most commonly discovered in LTC settings. The presence and influence of these patient, nurse, relationship and contextual factors has not been explored in CCC. Not only may these factors influence nurses’ experiences of this phenomenon, they may subsequently alter the ways in which nurses acknowledge the patient’s death and their preferences and the availability of support. These aspects will be explored in the following sections.

Nurses' Perceptions of Support and Individual Coping Strategies

Nurses' Perceptions of Support

In general, nurses in past research expressed a need and desire to discuss patients' deaths and to receive practical and emotional support (Katz et al., 2001; Rickerson et al., 2005; Wilson & Daley, 1998). In this review, activities were considered to be support if they involved education, capacity building or emotional support and reassurance, intended to sustain the well-being of nurses who care for patients at EOL.

Informal support.

Unstructured support resources not provided through the organization or by unit or nursing leadership were considered informal in this review. Informal support could broadly be broken down into categories of support from colleagues and support from non-colleagues, including from the nurse's family, friends and patients' family-members.

Support from colleagues.

Informal collegial support was the most common form of support described by nurses in the reviewed studies (Anderson et al., 2015; Gannon & Dowling, 2011; Katz et al., 2001; Hopkinson et al., 2005; Marcella & Kelley, 2015; Papatadou, 2000; Rickerson et al., 2005; Wilson, 2014; Wilson & Daley, 1998; Wilson & Kirschbaum, 2011). In addition to nurses supporting one another, other members of the healthcare team such as social worker and clergy were described to provide valuable informal support to nurses (Wilson & Daley, 1998).

Meaningful informal support from colleagues was often characterized by descriptions of a sense of acknowledgement, validation and inclusion (Anderson et al.,

2015; Hopkinson et al., 2005; Marcella & Kelley, 2015; Rickerson et al., 2005; Wilson, 2014; Wilson & Kirschbaum, 2011). Nurses benefited from recognition of their contribution to a quality EOL experience for the patient from the patient or their family members (Gerow et al., 2010). This type of positive feedback from nursing colleagues was associated with feelings of pride, pleasure and satisfaction in their work for nurses (Anderson et al., 2015) Sharing and confiding in other nurses and perceiving empathy and acknowledgement of their emotional reactions and the significance that losing a patient can have on nurses from colleagues were other ways the nature of informal support was described (Anderson et al., 2015). Role modeling from more experienced nurses was another form of collegial support that led to more positive experiences for nurses (Anderson et al., 2015; Marcella & Kelley, 2015). This included working alongside, being supervised and receiving practical support caring for patients from more experienced nurses, particularly in nurses' early experiences caring for dying patients (Anderson et al., 2015).

One study found that the nurses' perceptions of support from colleagues during patient death experiences was important to their overall perceptions of the experience as positive or negative (Anderson et al., 2015). On the other hand, nurses who felt unsupported by colleagues or who were uncomfortable seeking out their support reported on-going emotional distress after patient deaths (Anderson, et al., 2015). One survey study showed that although participants reported talking to colleagues as helpful, this support did not reduce their susceptibility to being negatively affected when patients die

(O'Hara et al., 1996). Collegial support may be important to nurses' experiences however to some degree, negative experiences when patients die may be inevitable.

Collegial support was the most commonly reported source of support and it was identified by direct care providers as being vitally important to their experience and well-being (Marcella & Kelley, 2015). This finding may suggest that nurses prefer informal support during patient death experiences. It could also represent a gap in adequate and acceptable formal resources such as Employee Assistance Programs or organized team debriefings following patient deaths. Regardless, simple acknowledgement of the nurses' emotions, experience and the care they provide to dying patients can enhance their feeling of being supported.

Support from non-colleagues.

A less commonly described type of informal support found in the literature was support from nurses' own family members, friends, and the patients' family members (Gannon & Dowling, 2011; Gerow et al., 2010; Rickerson et al., 2005). Gerow and colleagues (2010) found that a reciprocal relationship developed between nurses, patients and families surrounding the patient's death in which nurses experienced emotional support and recognition for their contribution to a quality EOL experience for the patient. Mutual support between nurses and patients' family members in LTC was found in another study (Gannon & Dowling, 2011). The *source* of informal support is critical to nurses' experience. As described earlier, support from people outside of the workplace or "ward family" is not perceived as beneficial because nurses feel that outsiders cannot understand their experiences (Gannon & Dowling, 2011; Wilson & Daley, 1998).

Formal support.

A common perception in the reviewed studies was that nurses perceived little or no formal support when caring for dying patients and after their deaths (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; Wilson & Daley, 1998). For the purpose of this review, formal support was considered any resource organized by the institution or provided by organizational leadership. Two studies found that participants felt they had to actively seek out this type of support (Copp & Dunn, 1993; Wilson, 2014). Another barrier to formal support is that nurses feel uncomfortable discussing challenges they face providing EOL care, fearing that it will lead to perceptions that they are incompetent providing this care (Marcella & Kelley, 2015; O'Hara et al., 1996; Wilson, 2014). In spite of this, three studies found that participants wanted and needed more formal emotional and practice-related supports for patient death (Katz et al. 2001, Rickerson et al., 2005, Wilson & Daley, 1998). Rickerson and her research team (2005) found that if available, over 50% of LTC staff would be willing to partake in additional formal supports such as attending individual counselling, using an online support tool, engaging in education about grief or attending a support group.

Two studies described an existing formal support in LTC which involved a partnership with a local hospice (Munn et al, 2008; Wilson & Daley, 1998). In one home, licensed nurses valued the expert hospice knowledge and perceived them as a source of training and bereavement support (Munn et al., 2008). Staff from the second study viewed the hospice staff as 'outsiders' and did not value them coming in and taking over the patient's care only at the end of their life (Wilson & Daley, 1998). A more in-depth

description of how support from local hospice organizations was employed in these homes is needed to better understand these conflicting findings. These findings also demonstrate the importance of exploring caregivers' perceptions of support interventions.

Three studies described that nurses and direct care providers desire that and benefit from their experiences being verbally acknowledged by preceptors and managers (Anderson et al., 2015; Marcella & Kelley, 2015; Wilson, 2014). This acknowledgement may also be indirectly communicated to nurses as two studies found that direct care providers felt that staffing levels and scheduling did not reflect or acknowledge the increased care needs of the dying patients, their family members, and the staff's needs providing that care (Katz et al., 2001; Marcella & Kelley, 2015). The theme of acknowledgement extends into formal support (Marcella & Kelley, 2015).

Support and education interventions.

Two studies retrieved in this search of the literature explored the perceived value of two formal support interventions in Canadian LTC settings (Maitland et al., 2012; Wickson-Griffiths et al., 2015). Wickson-Griffiths and colleagues (2015) conducted a qualitative descriptive study exploring LTC staff perceptions of Comfort Care Rounds (CCR). CCRs were a facilitated forum that provided palliative and EOL care education to interprofessional and paraprofessional LTC staff. CCRs also incorporated formal and peer support by acknowledging staff experiences and emotions and affirming their practice and knowledge (Wickson-Griffiths et al., 2015).

Both qualitative studies described participants' positive perceptions of the interventions (Maitland et al., 2012; Wickson-Griffiths et al., 2015). Room blessings

attendees found that their grief and emotions were validated during this ritual. The ceremony particularly helped ease the transition of ending care for the deceased resident and preparing to care for a future resident (Maitland et al., 2012). In semi-structured interviews and focus groups with 40 staff members, perceived outcomes of CCRs were found to be empowerment, improved confidence, community knowledge and increased knowledge of palliative and EOL care. CCRs served as an opportunity for staff reflection and this debriefing was described as therapeutic by staff (Wickson-Griffiths et al., 2015). Although the support intervention led to positive improvements for many staff, some staff noted no improvements relating to this intervention (Wickson-Griffiths et al., 2015). Similar challenges were faced in both studies, with scheduling and workload as barriers to staff attendance (Maitland et al., 2012; Wickson-Griffiths et al., 2015). These interventions may facilitate the aspects of informal support which nurses find meaningful while normalizing care providers' experiences. However, nurses may need multiple support opportunities that are tailored to their heavy workloads, scheduling and preferences for support.

The Gold Standard Framework (GSF) for Care Homes is a training and education accreditation program which aims to improve care of residents approaching end of life, improve coordination and collaboration among health care providers and improve cost effectiveness of this care by reducing hospitalization in LTC homes (National GSF Centre, 2016). LTC home staff attend four days of workshops and have access to care tools such as for advanced care planning. Evaluation studies have shown that care providers have greater knowledge and sense of empowerment (Badger et al., 2012) and

are more confident providing EOL care after receiving training (Ashton, McClelland, Roe, Mazhindu & Gandy, 2010; Badger et al., 2012). The GSF also seeks to transform care cultures and evidence suggests that caregivers' perceptions of their roles and responsibilities, the sense of team work, team collaboration and communication are positively influenced by this program (National GSF Centre, 2016). Available information on the program did not describe if recommendations are made to accredited homes for supporting care providers after patients die, however the potential influence of this program on organizational culture and team work may foster informal and on-going collegial support.

In summary, different formal and informal support strategies can help nurses make sense of dying and death as regular aspects of their practice (Marcella & Kelley, 2015). Informal support from colleagues provided important validation and acknowledgement to nurses' experiences of patient death (Anderson et al., 2015; Hopkinson et al., 2005; Marcella & Kelley, 2015; Rickerson et al., 2005; Wilson, 2014; Wilson & Kirschbaum, 2011). Formal support interventions can also benefit nurses when designed to show similar acknowledgement in addition to opportunities for closure or education (Maitland et al., 2012; Wickson-Griffiths et al., 2015). The source and nature of support are important to nurses' perceptions of support and it is important that nurses have multiple opportunities for support due to the nature of busy work environments and schedules. When facing inevitable patient death in CCC, it is important to understand the types of strategies that nurses employ and their preferences for support to maintain their well-being as they care for dying patients.

Individual Coping Strategies

Nurses employ a variety of personal strategies to manage their emotions surrounding the death of a patient. These strategies are often learned ‘on the job’ by watching other colleagues’ responses to patient death (Marcella & Kelley, 2015). The coping strategies used by nurses in the reviewed studies were; (a) cognitive strategies, (b) avoidance or distancing and (c) other personal strategies such as finding strength in spiritual beliefs.

Cognitive strategies.

Several cognitive strategies were used by nurses to manage their experiences of patient death. Two similar strategies were termed intellectualizing and rationalizing (O’Hara et al., 1996; Wilson, 2014). These approaches involved seeking to understanding the rationale for the person’s death such as disease process over the emotional burden that it may cause. Using these strategies, nurses also re-examined the details of the patient’s death to ensure they did everything they could for the patient, such as controlling their symptoms and being present for them (Wilson, 2014). Reframing the death event by emphasizing the positive aspects of the death, such that the patient was released from suffering and acknowledging that the nurse’s work contributed to a peaceful death are other examples of cognitive strategies (Marcella & Kelley, 2015; O’Hara et al., 1996).

A theory of how new nurses learn to cope with patient death identified measuring as a coping strategy of novice nurses (Hopkinson et al., 2005). Measuring was done in two ways; nurses would seek feedback from the patient or family member about the quality of the care they provided or they measured the death event against what their own

preferences would be for their death or a death of a family member. This comparison reassured novice nurses and helped them to maintain a sense of well-being during and after a patient's death (Hopkinson et al., 2005). A further strategy used by these participants included revising their beliefs about what represented an ideal death. More inclusive perceptions of a 'good' death reduced the potential complications that arise when nurses were unable to prevent 'bad' deaths (Hopkinson et al., 2005).

Avoidance and distancing.

Avoidance behaviours were described by nurses from different healthcare settings in response to participants' earliest patient death experiences (Anderson et al., 2015). Actions of avoidance included taking time off work, avoiding the type of setting in which the death occurred and some even avoided *any* clinical setting in which patients might die (Anderson et al., 2015). Three studies found that nurses coped by directing their attention towards more practical or technical responsibilities of nursing care (Anderson et al., 2015; Gerow et al., 2010; Hopkinson et al., 2005). Hopkinson and colleagues (2005) found that this was done to distract nurses from emotional thoughts about the patient dying. Another study found that nurses focused on tasks such as providing oral care or fresh bed linens in order to show caring for the patient and family while increasing their sense of control in the experience (Gerow et al., 2010).

Nurses distancing themselves from or controlling their involvement with the patient, their dying experience, and the potential emotions associated with it was found in many studies (Anderson et al., 2015; Gerow et al., 2010; Hopkinson et al., 2005; Marcella & Kelley, 2015; Sumaya-Smith, 1995; Wilson & Daley, 1998). Nurses distanced

themselves from patient death by attempting to separate their work and personal lives or intentionally distancing themselves from patients emotionally (Gerow et al., 2010; Hopkinson et al., 2005). Nurses in two studies described trying to avoid developing close relationships with patients (Anderson et al., 2015; Wilson & Daley, 1998). In Wilson and Daley's (1998) study, despite this effort, nurses found it nearly impossible to avoid these relationships in a LTC setting and working so closely with patients. At times, using dark humour or joking around with colleagues was referred to as a strategy that nurses employed to distance themselves from negative emotions, thoughts or grief in settings where patient death was common (Hopkinson et al., 2005; Marcella & Kelley, 2015; Wilson, 2014). These efforts towards distancing were intended to reduce the burden of the potential sadness and loss that can accompany the death of a patient.

Distancing is sometimes used by nurses because they believe that care of other patients may be negatively influenced if they become emotionally distressed about their dying patient (Hopkinson et al., 2005). However, some nurses in this study identified that distancing could compromise the care provided to the dying patient and their family. In another study, direct care providers maintained attachment until the patient died and then learned to 'detach' again following death in order to continue with their work (Marcella & Kelley, 2015). These findings tie back to the nurses' belief that close relationships are important to the delivery of quality EOL care (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; O'Hara et al., 1996; Wilson & Daley, 1998). This could represent a conflict for nurses who want to provide quality EOL care while preserving their own well-being and the integrity of care for other patients.

Other coping strategies and summary.

Marcella and Kelley (2015) found that nurses find comfort by simply spending time with and being present for the resident as they were dying. Making the resident comfortable in turn comforted them. Religious beliefs and spiritual well-being were personal coping strategies found in three studies (Gerow et al., 2010; O'Hara et al., 1996; Rickerson et al., 2005). These meaning-making strategies helped nurses to transcend the patient's death and understand it in new ways. Interestingly, 25% of 126 survey respondents identified that they use no coping strategy (O'Hara et al., 1996). A discussion of possible reasons for this was not explored by the authors. These findings might indicate that these care providers are uncomfortable reporting a coping strategy because it would suggest that they struggled with that part of their practice (Marcella & Kelley, 2015; O'Hara, 1996; Wilson, 2014). It may also be that some respondents have developed an acceptance of or resiliency to the inevitability of patient death and therefore need not employ specific coping strategies.

Nurses utilize a variety of informal and personal ways of managing their emotions and experiences following patients' deaths. Some of these strategies such as distancing and avoiding may be detrimental to patient care and lead to conflict for the nurse. In addition, the diverse and common use of personal strategies may indicate that additional support resources are required.

Literature Review Summary

This review of literature illustrated the potential complexity of nurses' experiences of patients' deaths owing to the unique interplay of patient, nurse, relationship and

contextual factors. The ways in which nurses' cope with, acknowledge and feel supported also influence their overall experience of patient death. Despite the significant finding that 42% of direct care providers in CCC were negatively influenced by patient death (O'Hara et al., 1996), no qualitative inquiry into nurses' experiences in CCC was found.

Understanding nurses' experiences of patient death and providing appropriate and meaningful support are important because future experiences caring for patients and families at EOL can be positively or negatively influenced based on their perceptions of early experiences (Anderson et al., 2015; Gerow et al., 2010). In addition, the findings from multiple studies suggest that grief and negative emotions can accumulate in nurses with more years of experience and that they are more likely to have challenging or negative experiences when patients die (Marcella & Kelley, 2015; O'Hara et al., 1996; Rickerson et al., 2005). The potential consequences of nurses' experiences include lost time at work, low morale, strained personal relationships, health problems and decreased efficiency at work (Anderson et al., 2015; Gibson et al., 2008; O'Hara et al., 1996). This means that nurses' experiences with this phenomenon not only influence nurses' well-being, but the delivery of patient care and organizational integrity.

The foundation of this literature review is knowledge generated in LTC. Significant setting differences exist in CCC and the setting and organizational context can influence nurses' experiences and need for support (Marcella & Kelley, 2015; Mezey et al., 2002). These differences include the age of and presence of cognitive impairment in the patient population, the length and closeness of relationships among nurses and patients and the recognition of CCC as a significant setting of death. Caring for younger

patients who die in CCC is related to more negative experiences for nurses (O'Hara et al., 1996). Closer relationships may develop between nurses and patients since patients in CCC have less incidence of cognitive impairment (CIHI, 2014) and the complexity of patients' physical care needs often means that regulated nurses provide more intimate care to fewer patients. For these reasons, deeper attachments may develop and nurses may be more likely to perceive patients' deaths as loss and experience grief (Gannon & Dowling, 2011; Gerow et al., 2010). Finally, LTC is more widely recognized as a place of resident death (Munn et al., 2008; Wilson & Daley, 1998) and this is evidenced by the growing body of literature exploring care providers' experiences. The single and dated study found in CCC (O'Hara et al., 1996) may indicate that CCC is not appropriately recognized as a significant setting where patients die, and suggests that the ethos of care and resources allocated to prepare and support staff to provide this care may be inadequate.

Beyond a gap of research conducted in CCC, a common limitation of the existing literature was a reliance on convenience sampling (Anderson et al., 2015; Gannon & Dowling, 2012; Gerow et al., 2010; O'Hara et al., 1996). This may have limited the ability of past studies to fully explore emerging findings and their significance. The findings may also only represent the voluntary sample and not wholly speak to the experiences of nurses. Past research also placed greater emphasis on negative and singular outcomes (i.e. grief) relating to nurses' experiences (Anderson et al., 2015; Gannon & Dowling, 2012; Gerow et al., 2015; Marcella & Kelley, 2015; O'Hara et al., 1996). A more holistic description of the range of ways that nurses may experience

patients' deaths is needed. CCC is a significant care setting for older adults, people with chronic illness and disability and will therefore continue to be an environment in which nurses grapple regularly with patient death (OHA, 2006). Novel knowledge must be developed in this setting to ensure nurses' well-being is protected and optimal care is provided to patients and their family members. A study design that fosters a holistic exploration of the phenomenon and the dynamics of the factors as tied to the context in CCC is important to first meaningfully understand nurses' experiences in order to make applied recommendations about nurses' support needs.

Research Questions

Based on this review of literature, four research questions were developed for further exploration in the current study. The overarching question of this study was: What are licensed nurses' experiences of patient death in complex continuing care? Secondary questions included: What are nurses' perceptions of the factors that influence this experience in complex continuing care? What do nurses do to acknowledge the death of a patient in CCC? Finally, what are nurses' perceptions of supports during this experience and what are their preferences for support?

CHAPTER 3

METHODOLOGY

Design

The experiences of licensed nurses working in CCC were explored using interpretive descriptive (ID) methodology (Thorne, 2008; Thorne, Kirkham & O’Flynn-Magee, 1997). This qualitative methodology supports inquiries into the health and illness experiences of people from an applied health perspective (Thorne et al., 1997; Thorne, Kirkham & O’Flynn-Magee, 2004; Thorne, 2008). ID assumes that these experiences result from complex interactions among psychosocial and biological domains of the person. The naturalistic and constructivist orientation of ID recognizes both the individual and constructed realities of health and illness experiences; it acknowledges that aspects of this subjective reality may be shared among people with similar experiences (Thorne et al., 1997). ID was selected to address the research questions because it allowed for both description and interpretation of nurses’ shared experiences of the phenomenon, while generating findings that remain applicable to clinical practice (Thorne, 2008).

Critical incident technique (CIT) is a systematic set of procedures which can be used to facilitate an understanding of everyday practical problems, supported the design of this study (Flanagan, 1954; Janes et al., 2009; Kemppainen, 2000). Critical incidents are memorable “events, activities or role behaviours, which affect the outcomes of [a] system or process” (Schluter, Seaton & Chaboyer., 2008, p. 108). For this study, a critical incident was defined as any memorable patient death experience which occurred in CCC. CIT was selected to structure data collection because it aligns with the commitment of ID

to produce readily applicable knowledge in order to address everyday clinical problems (Thorne et al., 1997). Seeking incidents of memorable patient death supported the collection of more reliable experiential data (Anderson et al., 2015; Flanagan, 1954; Schluter et al., 2008). It has been used in past research to explore health care professionals' perspectives of phenomena relating to patient care (e.g. D'Hondt, Kaasalainen, Prentice, & Schindel Martin, 2012; Hunt, 2009; Narayanasamy & Owens 2001; Norman, Redfern, Tomalin & Oliver, 1992).

Setting and Participant Recruitment

Study Setting

Data was collected from licensed nurses from two units within a CCC hospital in southern Ontario. This hospital was chosen because of its university affiliation and support of clinical research. One unit had 25 patients with care provided by one RN and four RPNs on day shifts. The second unit had 33 patients with care provided by one RN and two RPNs on day shifts. Personal support workers were recently added to the care team on this unit and supported nurses to provide personal care to patients. These units were selected for the study setting because they cared for a diverse patient population with multiple or complex medical needs. This population is understudied and it was speculated that nurses working in this service would have different experiences with patient death than nurses working in specialty CCC services such as low tolerance long duration rehabilitation or palliative care.

Participants

Participants were licensed nurses (RN/RPN), the majority of whom provided direct care to patients. Both RNs and RPNs perform the same four controlled acts under the Regulated Health Professions Act (1991) (CNO, 2014a). In CCC, nurses provide skilled and technology-based medical care, in addition to assisting patients with activities of daily living. Their scope and autonomy in practice differ based on the complexity, predictability and potential for negative outcomes relating to a patient's care (CNO, 2014a; HealthForceOntario, 2015) and roles defined by the organization. Additional participants included nurses in case manager and advanced practice nurse (APN) roles. Case managers were RNs who managed the admission, care plan and discharge activities of patients in addition to facilitating communication between health care team members, the patient and their family members. APNs have graduate-level education and provide clinical leadership through synthesis of in-depth knowledge of clinical practice, theory, research and education (Canadian Nurses Association [CNA], 2008). Participants in these roles were referred to as nursing leaders and were included to explore the phenomenon of patient death from different nursing perspectives.

Nurses were selected for this study because they have longer and closer contact with patients and their family members than other health care professionals (Costello, 2001). This proximity to the patient supports the development of close relationships which have been described as family-like (Gannon & Dowling, 2011; Munn et al., 2008; Sumaya-Smith, 1995; Waldrop & Nyquist, 2011; Wilson & Daley, 1998). PSWs that provided care on one of the units were not included because they were added to the care

delivery model during recruitment. The novelty of this role meant that the PSWs were unfamiliar with the clinical context and patient population at the time of the study. Finally, developing knowledge and understanding of shared subjective experiences was facilitated by studying experiences of people with similar educational and practice backgrounds.

Recruitment

Initial contact with the study site was made through email correspondence with a nursing leader and unit manager from the aforementioned units. The study purpose, activities and recruitment strategies were discussed during telephone and in-person meetings with the unit manager. The unit manager forwarded a recruitment email (see Appendix D) to all nurses from both units and placed recruitment posters in common areas such as the nursing lounge (see Appendix E). Participants were actively recruited through weekly visits to the clinical units by the student investigator. Study information was shared directly with nursing staff and if they were interested in the study, permission was requested to contact them through their work email address to arrange an interview. One nurse replied to the email recruitment and six participants were recruited through weekly visits to the unit.

At the end of each interview, participants were asked if they would participate in a follow-up interview. Five participants agreed to be contacted again and two responded to email communication to participate in a follow-up dialogue about emerging findings. Following the first six interviews, early themes suggested nurses' experiences were influenced by their years of experience and that male nurses may have different

experiences of support. An APN was asked to support recruitment of nurses with two or less years of experience and additional male nurses. One additional participant was recruited in this fashion.

Sampling

A hallmark of qualitative inquiry is purposeful sampling. This approach relies on a small number of information-rich participants who are specifically chosen to explore the central phenomenon (Patton, 2015). Purposeful sampling is critical to ensuring that participants' individual experiences can contribute to a shared understanding of nurses' patient death experience (Thorne et al., 1997). Criterion and theoretical purposive sampling were used to identify participants who had experienced patient death in CCC and who were able to articulate their experiences (Patton, 2015).

Criterion Sampling

Participants were eligible for inclusion if they were: (a) a practicing RN or RPN with a minimum six months of experience providing direct care to patients in CCC; (b) proficient in spoken English; and (c) able to communicate details of a patient death experience. Nursing leaders were: (a) licensed RN or RPN; (b) working in a nurse leadership position; and (c) proficient in spoken English. These criteria ensured that critical incidents of a patient death experience relevant to the study setting and purpose were captured (Patton, 2015). Critical incidents were foundational to understanding the experiences of nurses in CCC and inclusion of these real-life experiences strengthened the applied focus of ID. No participant accounts were excluded from the findings. However, the criterion for length of experience was reduced from a minimum of one year to six

months of working in CCC after early findings highlighted the importance of different experiences of death for novice and experienced nurses.

Theoretical Sampling

Theoretical sampling is an important sampling strategy in ID (Thorne, 2008; Thorne et al., 1997). Theoretical sampling involves purposefully recruiting participants who demonstrate varying aspects of a developing theoretical construct (Patton, 2015). Early analysis of interview data from six participants who had six or more years of experience and were over 40 years of age suggested that nurses were accepting of patients' deaths. In addition, the voice of one male participant challenged the finding of strong collegial support among nurses in patient death experiences. Thus, during on-going recruitment, younger nurses with fewer years of experience and an additional male participant were sought to further explore these findings. In subsequent interviews, participants were probed to share more negative or challenging experiences. Two participants and four incidents were theoretically sampled according to these criteria.

Sample Size

Multiple considerations were made when determining the final sample size. Using CIT, critical incidents form the unit-of-analysis rather than the number of participants (Cormack, 1991; Flanagan, 1954). Typically, saturation is achieved when there is redundancy in analysis of categories or properties of incidents and a comprehensive description of the phenomenon can be portrayed, signalling the researcher to stop data collection (Kemppainen, 2000; Norman et al., 1992; Patton, 2015). CIT was used as a tool to explore nurses' experiences in an interpretive description design, and thus the

concept of saturation alone was not adequate in determining sample size (Thorne, 2008). In ID, sample size is determined by what is needed to address the research questions and to satisfy the purpose of the study. It is driven by concurrent data collection and analysis, and theoretical sampling (Thorne, 2008).

In this exploratory study, which sought depth in richly describing nurses' experiences, 13 memorable experiences from nurses' practice were considered appropriate (Patton, 2015; Thorne, 2008) and consensus from thesis committee members was reached to support this decision. Based on the complexity of factors influencing nurses' experiences and the sensitivity of the topic, it was determined that it was more valuable and feasible for a masters-level thesis to re-interview two participants to probe further into their experiences as opposed to seek more breadth in incidents and participants. In addition, engaging with a participant on multiple occasions supported the development of a shared understanding and higher quality data (Chirban, 1996).

The preliminary sample size estimate was that 8-12 participants were needed to reach data saturation and a new understanding of the phenomenon. A priori, two or three participants were intended to be nursing leaders in order to provide an alternative source of perspectives on the phenomenon while strengthening the disciplinary nursing lens. Participants were asked to share one critical incident from their practice in the interview. A total of eight participants were interviewed and two participants partook in follow up interviews.

Data Collection

Collecting data from a range of data sources is valuable in the development of applied health knowledge using ID (Thorne et al., 1994; Thorne et al., 2004). In-depth, semi-structured interviews occurred with licensed nurses who experienced patient death in CCC. Interviews with nursing leaders broadened the nursing perspective on the experience of patient death and added contextual information about the local setting (See Appendix F and G for Direct Care Nurse and Nursing Leadership Interview Guides). Interviews were 40-60 minutes in length. Follow up interviews occurred with two consenting participants in order to share emerging understandings of the data with participants and collect additional incidents. Their insights and co-reflection supported on-going analysis (Thorne, 2008; Thorne et al., 1997). Basic demographic information of all participants was collected in survey form to support data analysis, enabling comparison of the findings to past research (See Appendix H for Participant Demographic Questionnaire). Data were collected from November 2015 to February 2016.

Interviews

Interviews are a common method of data collection in qualitative research. They are necessary for collecting data about unobservable phenomenon and learning about a person's or group's experience of a phenomenon and the meaning attached to it (Patton, 2015). Retrospective collection of nurses' experiences through interviews was required because the thoughts, feelings and implications associated with patient death are not observable (Anderson et al., 2015; Narayanasamy & Owens 2001; Patton, 2015). In this study, interviews led to the collection of rich experiential data from participants and

allowed for further probing into participants' responses (Schluter et al., 2008). Further, interviews align with nurses' oral culture and support reflection on the event by the participant (Schluter et al., 2008). Finally, exploring patient death experiences through in-person interviews allowed the researcher and participants to move beyond the details of the death event and nurses' experiences towards a deeper exploration of the meaning of these experiences (Chirban, 1996, Thorne, 2008).

Prior to data collection, the interview guide was piloted with a direct care nurse. This aided simplification of the language used in the questions and was an opportunity to practice question delivery. Following the first three interviews, additional probes were added to the interview guide to explore evolving themes. In latter interviews, more emphasis was placed on the nurses' experiences being memorable rather than the patient's death event being memorable because early interviews showed that the incident may have been important or meaningful to nurses for diverse reasons unrelated to how the patient died. In addition, examples or suggestions given by other participants were shared with participants to encourage reflection and were used to develop study recommendations from the voice of nurses. Early transcripts were reviewed by the study supervisor and feedback and interview coaching were provided to support on-going data collection. Two follow up interviews were conducted to collect new data about negatively perceived or unexpected incidents of patient death. Additional data collection was done in follow up interviews because many early incidents focused on positive experiences.

Each participant was asked first to share details of a memorable experience from their practice when a patient died. I probed for both positively and negatively perceived

death experiences during interviews (Flanagan, 1954; Janes et al., 2009; Kemppainen et al., 1998). This promoted a more holistic understanding of the phenomenon and of how nurses may be influenced by patient death (Cormack, 2000). A series of open-ended questions followed which explored how the participant felt, their actions and perceptions of support during and after the experience. Participants were also asked to reflect about the meaning and influence that this experience had on their lives and practice. Seeking incidents of memorable patient death supported the collection of more reliable experiential data (Anderson et al., 2015; Flanagan, 1954; Schluter et al., 2008). In addition, more extreme events are easier to recall (Schluter et al., 2007). Critical incidents were referred to as memorable events in this study relating to the negative connotations of ‘critical’ and ‘incident’ in healthcare settings (Schluter et al., 2008).

Interactive-relational (IR) approach.

Qualities of the IR approach to interviewing aided the collection of interview data and reflection on participant interviews. This approach promoted engagement with participants, contributing to a deeper understanding of their experiences (Chirban, 1996; Schluter et al., 2008). Prior to conducting interviews, I reflected on my past experiences with death in addition to my values, beliefs, motivations and assumptions related to the phenomenon in order to develop self-awareness. I was intentionally authentic and open with participants during the interviews and integrated personal characteristics such as humour and showing caring in the interviews to support an authentic exchange (Chirban, 1996).

I was attuned to participants by preserving the context of their responses and seeking their experience within the incident they reported. Further, I permitted the interview to naturally move beyond the set interview guide to explore the phenomenon according to the interviewees' needs, in recognition that the pre-planned interview guide may have been inadequate to explore fully their experiences (Chirban, 1996). Ultimately, this approach encouraged the integration of personhood into the interview and deepened the rapport between the participants and me, thus leading to richer data, co-reflection, and development of a new understanding of the phenomenon (Chirban, 1996; Schluter et al., 2008). The preservation of context and space to co-reflect with participants in the new interviewer-interviewee relationship complemented ID methodology.

As an interviewer, I recognized and was transparent about my past clinical experience and few experiences with death. Participants were treated as experts of the phenomenon (Chirban, 1996; Thorne, 2008). Clarification and summarizing were used to support the developing understanding of each nurse participant's experience. I used my past clinical experiences and evolving understanding of the phenomenon from other participants to probe and reflect my interpretations back to participants during the interviews. I then summarized and sought confirmation that my interpretations were correct, both within the interview and in follow up interviews. Following each interview and during transcription, I reflected on the interview and my use of IR principles. This facilitated identification of strategies to improve application of IR in subsequent interviews. The openness of this approach was critical to emergent analysis and the

evolving understanding of critical patient death experience in CCC. Without extending and sharing power in the interviews, this opportunity would likely have been missed.

Data Analysis

All interviews were electronically recorded. Early analysis commenced immediately following each interview by way of journaling and handwritten field notes. Recordings were transcribed verbatim using Express Scribe Transcription Software by the student researcher. This supported early data analysis through data immersion (Patton, 2015; Thorne et al., 1997; Thorne et al., 2004). Early connections and patterns were captured in memos alongside transcription as familiarity with the data deepened. Each transcript was read an additional time prior to coding. All transcriptions were uploaded and managed in Dedoose, a web-based data management application (Dedoose, 2014).

Data analysis followed an inductive approach (Thorne et al., 1997; Patton, 2015). This involved working with the data until new understandings, explanations or concepts surrounding the phenomenon were generated (Patton, 2015). Cornerstones of data analysis in ID are “constant comparison, iterative analysis and reciprocal approaches to data making and analysis” (Hunt, 2009, p.1288). Three early transcripts were coded by my supervisor and me to develop a preliminary coding scheme. Two of these transcripts were also coded by the remaining three committee members. Discussion among the committee fuelled coding chart revisions. A working draft of the coding chart with 15 main codes was presented back to the committee and coding commenced with their approval (see Appendix I). Analytical breadth was sought over detailed coding or line-by-line analysis (Thorne et al., 2004). Large sections of transcripts were coded to preserve

context and multiple codes were applied to each excerpt in recognition of the complexity of nurses' experiences. These approaches facilitated looking at the data holistically by asking of it questions such as, "What is happening here?" (Thorne et al., 1997, p. 174). Memoing occurred alongside coding and included ideas about early patterns, how excerpts related to or contrasted to another participants' transcripts and on-going questions about nurses' experiences. New codes were added to address gaps in later transcripts, some codes were collapsed together and code definitions were expanded and redefined as immersion in the data continued. The final coding scheme contained 19 main codes (see Appendix J).

Analysis oscillated between looking from individual nurse experiences out to the sample's shared experiences, from one aspect of nurses' experience (ie. perceptions of support) back out to the total experience, and from data analysis back to data collection (Thorne, 2008; Thorne et al., 2004). These iterations were driven by constant comparison (Thorne, 2008; Thorne et al., 2004) an analysis technique which involves juxtaposing data bits with one another and with emerging interpretations to look for similarities and differences across and between participant experiences (Patton, 2015). This was facilitated by tools in the Dedoose program which allowed me to pull all excerpts where the same code was applied and compare them against one another. Maintaining an overall macroscopic view of the data throughout analysis assisted in conserving the context of nurses' experiences (Thorne et al., 1997; Thorne et al., 2004).

Several strategies were used to test early patterns and outlier data during data analysis (Patton, 2015; Thorne et al., 2004). First, I looked for examples in the existing

study data and past empirical literature that conflicted with or supported this pattern, and asked myself ‘Why am I seeing this pattern?’ (Thorne, 2008; Thorne et al., 1994; Thorne et al., 1997). I added probes to the interview guide to gather participants’ reflections on these patterns in subsequent interviews (Thorne et al., 1997). Theoretical sampling facilitated flushing out early patterns and seeing if the pattern was consistent across different types of participants (e.g. novice nurses) and different types of patient death experiences (e.g. negative experiences). One early pattern suggested that nurses’ experiences when patients died in CCC were more frequently perceived as positive and that they were overall accepting of patients’ deaths. By theoretically sampling for participants with more negative experiences and directly asking a participant about this finding in a follow up interview, some participants said that they were uncomfortable re-telling negative experiences and thus preferred to share positive experiences. Another strategy involved returning to the raw data of five interviews following coding of all transcripts with the coding scheme (Thorne, 2008). Returning to the raw data involved re-analyzing five diverse transcripts by writing memos and reflections as I read the transcripts to search for alternative understandings of nurses’ experiences (see Appendix K for Analysis Examples of Coding and Returning to Raw Data). This activity was critical for evolving early patterns and codes into themes and resulted in new understandings of how the key themes related to one another.

Follow up interviews were also a significant strategy of testing and evolving my analysis. In these interviews, I shared some early patterns in the data with participants, using examples from their first interview to illustrate my interpretations. I then sought the

participants' perspectives on my analysis and other possible explanations for the findings as the interview proceeded in a two-way dialogue. In one of these interviews, I showed an example of an early conceptual map to the participant as I described some of the evolving themes. I reflected upon how these interviews supported or challenged my current analysis. Alternative sense-making activities included concept mapping, theorizing outliers and external critiques. Concept maps were often used during analysis to explore the possible interconnections among themes (Daley, 2004). Despite probing, no incidents of patient's death following cardiopulmonary resuscitation were collected. Thorne (2008) recommends theorizing potential outliers and envisioning how they might influence data analysis. Since most collected incidents were of expected and peaceful deaths, it was hypothesized that a patient dying in an emergency code would be distressing and potentially conflicting to nurses in CCC. Finally, intermittent external critiques of on-going analysis were conducted by the thesis supervisor (Thorne, 2008) and evolving analysis and decision-making were regularly shared with the supervisory committee. Reflection on this feedback challenged me to deepen analysis and consider alternative perspectives in interpretation (Thorne, 2008).

An analysis journal in the form of a blank notebook was maintained from study conception to the end of analysis. This journal tracked all analytical decisions (Patton, 2015) serving as both an audit trail (Birks, Chapman & Francis, 2008; Lincoln & Guba, 1985) and as a forum to capture my personal and emotional thought processes while conducting the study (Thorne, 2008). This journal was used to capture field notes, memos during transcription and coding, and concept maps. I also used the journal to support

analysis in different ways such as by making lists of things that surprised me from the data, identifying data that did not seem to fit into my current interpretations and noting obvious outliers. When I felt ‘stuck’ in my analysis, I would write in my analysis journal about things that I did not understand and I reviewed older entries to see if there were other field notes or reflections that could support my problem solving.

Rigour

This study used strategies to promote trustworthiness and enhance rigour as directed by Lincoln and Guba’s (1985) seminal criteria. These criteria were selected because they shared philosophical roots in naturalistic inquiry along with ID (Caelli et al., 2003; Thorne et al., 2004). The goal of these activities was to make the analytic process and methodological decisions explicit throughout the research study (Thorne et al., 1997).

The criterion of credibility speaks to the truthfulness of the study findings (Lincoln & Guba, 1985). Credibility was supported by gathering participants’ reflections and insights on emerging findings in follow up interviews with willing participants (Thorne et al., 1997; Thorne, 2008). This method of challenging the findings supported co-construction of new data with participants in addition to validating early interpretations (Patton, 2015). Credibility was further enhanced through analyst and data source-triangulation (Lincoln & Guba, 1985; Patton, 2015). This involved five analysts coding the first two transcripts and analysis was monitored by my thesis supervisor (Patton, 2015). Data source triangulation involved converging on the findings in RN, RPN and nurse leaders’ perspectives of the phenomenon (Patton, 2015).

Transferability is achieved when research consumers are able to make informed decisions about the applicability of the findings to their respective contexts (Lincoln & Guba, 1985). A thorough description of the participants and the study setting are presented in the thesis and will be included in subsequent publications (Lincoln & Guba, 1985). The potential for this study's findings being used to understand nurses' experiences in other settings is increased because of the diverse participant characteristics and patient death experiences collected.

When study findings are grounded in the experiences of the participants and not in the investigator's motivations and biases they are considered confirmable (Lincoln & Guba, 1985). Analyst triangulation and follow up interviews with participants further reduced the chance of investigator bias during analysis. An auditable analysis journal was kept which captured methodological decisions and the investigator's reflections. Beyond the analysis journal, pertinent study design and analysis decisions are transparently contextualized in the written thesis (Caelli et al., 2003; Emden & Sandelowski, 1998; Thorne et al., 2004).

Ethical Considerations

Patient death memories can be vividly recalled and as a result, some participants became emotional during interviews (Anderson et al., 2015; Gerow et al., 2010; Sumaya-Smith, 1995). Past studies have shown that nurses and other care providers are hesitant to discuss implications of patient death on their practice or personal lives because they do not want to appear unprofessional or incapable of handling this inevitable part of their role (Marcella & Kelley, 2015; O'Hara, 1996; Wilson, 2014). In addition, persons with

recent personal losses are more negatively affected by patient death (O'Hara et al., 1996). In response to these factors, several measures were taken in order to protect the well-being and confidentiality of participants in this study. During recruitment, I explained thoroughly the nature of the interview and engaged all participants in informed consent (see Appendix L for consent form). At this time, it was reinforced that they were free to withdraw from the study at any time and that their participation and experiences would be protected in confidence. Breaks during the interview were permitted and encouraged. Three participants cried during the initial interviews. After a short break, they were willing and able to continue.

I offered to meet participants in a neutral and private location of their preference, however all interviews were conducted in the continuing care hospital, in a private room away from the clinical unit. At the conclusion of the interview, all participants were asked if there was anything else they wanted to discuss and if they were comfortable returning to work after the interview. I was prepared to provide participants with the contact information for the Employee Assistance Program if participants indicated a need for additional support or encourage them to speak with a trusted colleague, the hospital's spiritual care providers or a unit social worker. Evidence suggests that nurses benefit from speaking to organizational social workers or chaplains (Wilson & Daley, 1998) and other nursing colleagues about their experiences (Anderson et al., 2015; Gannon & Dowling, 2011; Katz et al., 2001; Hopkinson et al., 2005; Marcella & Kelley, 2015; Papatadou, 2000; Rickerson et al., 2005; Wilson, 2014; Wilson & Daley, 1998; Wilson & Kirschbaum, 2011).

All participant data were identified by an identification code. All identifying information was kept secured in a locked cabinet and in an encrypted document on a password protected computer. All paper and electronic identifying information were destroyed upon study completion. De-identified transcripts and analysis notes will be kept for five years with participant consent. A \$10 gift card to Tim Hortons was provided to participants at the start of the interview as a gesture of gratitude for their participation. This study was approved by the Hamilton Integrated Research Ethics Board (project number 0717).

CHAPTER 4

FINDINGS

Participant Characteristics

Of the eight participants, half were RPNs, 25% were RNs and the remaining 25% were RNs in leadership positions (i.e. case manager, advanced practice nurse). Female participants made up 75% of the sample. Participants ranged in their years of nursing experience. Two participants had approximately one year of experience, three had 6 to 10 years, and three had more than 16 years of experience. Most participants had worked in CCC for the span of their careers (see Table 2 for Participant Characteristics).

Overview of Major Findings

Analysis of the diverse critical incidents uncovered five key themes that shed light on nurses' experiences when patients die in CCC. Nurses described these experiences as: Professionally experiencing patients' deaths: 'Engaging your left brain;' Personally experiencing patients' deaths: 'I'm a human being too;' and Seeking resolution in the experience: 'It was a good resolution.' Beyond each patient death experience, nurses' experiences culminated in a journey over time, leading to nurses' growth as described in the theme: Integrating professional and personal experiences: 'Applying what you learn in your nursing life into your personal life and vice versa.' Finally, nurses' experiences occurred in a cultural milieu which encompassed the support they received and ways in which patients' deaths were acknowledged which is captured in the theme: Supporting one another in a culture of acknowledging patients' deaths and nurses' experiences: 'They expect us just to take it, the nursing profession is like that' (see Table 3 for Themes

and Subthemes). Embedded in these themes were key factors which influenced nurses' experiences including past experiences with death and years of nursing experience.

Prior to presenting the key themes, participants' memorable patient death experiences and key features of the research context from participants' perspectives will be described to support understanding of the study's findings and to facilitate decisions of transferability to other settings. Feminine pronouns will be used to refer to all participants throughout this chapter to protect the participants' anonymity.

Memorable Incidents of Patient Death

A total of 13 critical incidents were collected, six were defined by participants as having gone well or being a positive experience and the remaining seven incidents were perceived as negative or challenging experiences. Three participants shared two critical incidents during initial interviews and one participant shared two additional incidents during a follow up interview. Ten incidents were explored in great detail during interviews and were central to data analysis. Three additional incidents were important to understanding nurses' experiences of patient deaths but were not explored to the same depth because they were elicited later in the interview (see Table 4 for Memorable Patient Death Incidents).

The incidents occurred as recently as one week to 15 years before the interview occurred. Participants defined these experiences as memorable because it was their first patient death, they had a close relationship with the patient, or there were unique circumstances surrounding incident. The incidents described different aspects of an EOL care continuum including: the moments leading up to and the patient's death, providing

after death care and learning about the patient's death after it occurred. Some participants found it therapeutic to explore their past experiences and appreciated the rare opportunity to reflect on them.

Context of Setting and Participants

An introduction to and overall sense of the research setting is captured by the following quote that depicts the hospital as:

A more relationship-centered, homey, family-feeling kind of place...there is a culture of establishing and maintaining relationships with patients and their families... because of the pace and our ability to be able to do things in a way that that makes people feel like we're quite person-centred, family-oriented. (#03; Nurse Leader)

From the perspective of the study participants, the hospital was the patients' home. Their approach to care therefore reflected this philosophy and nurses strove to provide nursing care in a way that respected the person and family. One novice nurse expressed this value:

Even if you're feeling crappy, just put a smile on your face... You at least get to leave and go home, they [patients] don't, they are home... They never leave, you're guests in their home. (#07; RPN)

Nurses described how patients in CCC required complex intervention and support and most patients depended completely on nurses to meet their activities of daily living. This workload was described by participants as being 'heavy,' 'busy' or 'crazy.' For nurses, particularly those with less experience, it was challenging to balance the demands of the unit while trying to meet the care needs of a patient and their family at EOL.

Our floor is very hard, it's very heavy, you have to get things done and we find the ones [nurses] like me who have been there a long time, we like to give our patients certain level of care where newer staff don't have that yet. (#06, RPN)

Patients had diseases such as multiple sclerosis (MS), Parkinson's disease, Huntington's disease and chronic obstructive pulmonary disease. One RN illustrated the progressive function loss and illness trajectory of a patient she knew for many years:

Seeing the debilitation that she had when I saw her as a student until 3 years ago and then even more deterioration when I came back here 7 months ago. Just to see how advanced her MS was, how her communication abilities had changed...how her personality had changed. Everything completely changed. (#05; RN)

Nurse-Patient Relationships

All patients described in the incidents had been in CCC for many years prior to their deaths. Throughout these long lengths of stay, close relationships naturally developed between nurses and their patients. One participant captured the depth of nurses' knowing their patient when they said:

We see them every day. We sit beside them every day. They tell us what they like. Sometimes, they tell us so much about their childhood stories, school stories, and when they found a girlfriend. They tell us everything. We know them. I can write a book about each of my patients. (#01; RPN)

These caring relationships are promoted in a setting which was considered by the participants to be the patient's home and can be seen as inevitable due to the length of time and intimacy of nurses' and patients' interactions. Close relationships with patients' family members were also described and for some patients, nurses were the only family that they had.

Types of Death

Participants perceived that patients died infrequently in comparison to the palliative care unit within the hospital. It was however acknowledged that most patients

stayed in the setting until they died. One participant illustrated the nature of death in CCC, connecting it to the relationships that develop between nurses and patients:

I think in our setting, many of the people are end-of-life, sometimes it is a prolonged end-of-life, but it is end-of-life...by definition, people are here at the end of their lives...our deaths are much fewer and farther in between, but our relationships with patients are much longer...there's a lot longer to establish relationships and a lot longer to be in a relationships...our nurses watch them decline (#03; Nurse Leader)

This quote describes that nurses accompany their patients over the course of a prolonged journey towards death in CCC. Two other types of death experiences were captured in critical incidents and they included unexpected deaths and when patients die in acute care.

Unit Turnover

Patient turnover was relatively low in these CCC units. Following a patient's death however, participants described that a new patient was quickly admitted to the available bed. This demonstrates the high demand for this service. One RN captured the swiftness of turnover when she said, 'You don't even have time to grieve, the bed's not even cold and you're bringing somebody else in' (#02; RN/Nurse Leader). Death ends years-long relationships between nurses, patients and their family members and nurses must adapt quickly to a new patient.

Professionally Experiencing Patients' Deaths: 'Engaging your left brain'

Participants often emphasized the aspect of their experience that involved caring for the patient, facilitating the experience of the patient's family and following unit and organizational procedures. These activities centered on interpersonal interactions with the

patient and family and on their roles and responsibilities as a nurse. Three themes relating to nurses' experience of their role will now be explored. One participant characterized this aspect of the experience as 'left brained,' which referred to the busyness of competing demands and multiple roles that nurses assume in the time surrounding patients' deaths.

Protecting the Patient: 'So much love, so much supervision'

Participants all prioritized the patient's care at EOL. Nurses in CCC carried a sense of duty to the patient to protect them from suffering, protect the patient's dignity and protect them from dying alone. The participants described giving dying patients special attention, which went above and beyond routine care. The care philosophy of participants was to treat the patient how they would want their own family member treated, and as 'one of their own'. One participant affectionately described this approach to care when she said, "When I see somebody so sick, I really get very close so he can get my attention, so much attention. So much love, so much supervision....As much as I can" (#01; RPN). A second participant emphasized this point adding the importance of protecting the patient's dignity. She described instilling this value in nursing students and new staff members:

Give the care that you'd like to see someone get... the extra mouth care, the extra this or that, pamper them ...they may go at any minute. Make them look the best that they can... I always tell students when they come here to treat them as if they were a family member ...you want them to look like they should look...with respect, you want them to be respected. (#06; RPN)

The participants' duty to protect their patients at EOL was evident in the way nurses described the extent of their efforts to prevent a patient from dying alone. One nurse described this when she said:

Everyone should have somebody there... I remember going into a room once... I called up to the front and I said, 'He's going, he is on his way out,' and you know you can't leave, you have to stay there because otherwise you're going to walk away and they're going to be dying without someone there with them. (#02; RN/Nurse Leader)

When the nursing team was unable to protect the patient from suffering, dying alone or loss of their dignity, they recalled their experience as negative and continued to show upset and sadness when recalling the experience. One participant reflected on her sense of duty when she felt her patient had prolonged suffering as he died, "I'm a nurse, I'm here to save the lives. That is my understanding, being a nurse, I should save lives. I should not let anybody go through any kind of pain, as much as I could control it" (#01; RPN). She later questioned why this patient suffered, "So why could I not save him?" Therefore, the participants' first priority was fulfilling their role of protecting patients and this was fundamental to how they perceived their experiences.

Preparing and Supporting Families: 'Shifting my focus to the family'

Several critical incidents centered on the nurses' experiences of caring for patients' family members and all participants reflected on family care surrounding the patient's death. Examples included anticipating a family member's reaction to the patient's death, supporting them to say goodbye, following the family's wishes for care of the patient's body and belongings and worrying about how the family

will cope with grief after they leave the setting. One participant generally described the role of the nurse in caring for families:

It's supporting the family while you support the patient...it's talking to the families, just the support and actually giving them some idea of what's going to happen, you know, giving them a framework. (#02; RN/Nurse Leader)

Typically, when the nurse perceived that the family would cope well after the death, the nurse described their own experience as positive. When the nurse had no concerns about the patient's experience, their attention 'shifted' to the family as described by one participant:

That's one thing, we found with him because he was getting close and it was fine his death...I was more like, 'what will happen with her [patient's wife] at that point?'...that was more our concern. (#04; RPN)

The participants' experiences of supporting family varied depending on their past experiences and comfort. One nurse with one year experience described her uncertainty and discomfort emotionally supporting families:

Speaking with the family I didn't know, do I hug you? Am I too forward if I hug, what do I do?...that was tough to try and figure that out and I don't think I have yet...cause I don't have enough experience I guess...My emotions are very wrapped up inside so just like when someone's pouring out emotions I'm just like, 'what do I do? (#08; RPN)

In contrast, a participant with more than six years of experience, who also went through the death of a parent as a young adult described a positive experience of supporting a patient's close friend;

I just encouraged the other person, 'say whatever you want to say'...her friend was uncomfortable so I sensed that and she said she was grateful that I was there... I made it better for her, to kind of walk her through it, just you know make her more comfortable, tell stories, and just share...it was nice. (#06; RPN)

Following a patient's death, the concern and care for patient's families were on-going. Some nurses continued to wonder how a family had coped, particularly if there was no communication back to the nursing team after the patient's death. The 'shift' in attention is described by a second participant whose concern centers on the family's well-being after the patient's death:

I really feel more sorry for her family because, that's where my energies will be focused more...my focus would be shifted to her family and just hoping that they're ok and that they're dealing with things. Not everybody deals with death and dying that well. I guess it depends on what you've been through in life and...the experiences you've had. (#05; RN)

Nurses described that the role of the nurse was to guide the family through this experience. Their experiences were therefore closely tied to their perceptions of the family's journey and their ability and comfort in providing support to family members.

Following Policy and Procedure: 'We have to talk about practicalities'

In addition to balancing the care needs of patients and families, nurses described the procedures involved in their experience such as documentation and the practical considerations of caring for the patient's body after death. One participant captured the range of tasks that the nurse coordinates following a patient's death:

At the time you're too busy, you're doing everything, you're engaging your left brain. You're so involved in the practical aspect of it. There is a whole protocol you have to follow, a whole way you have to chart. There are things you have to do, and there's the logistics of when the family is gone. I give them a framework of what I expect from them. We have to talk about practicalities and what has to happen now. (#02; RN/Nurse Leader)

A second participant echoed this and spoke about her experience after a patient died:

You follow the procedure...At the beginning of the shift, they come from security to take them [the patient's body] to the holding room. We always escort the body...You know when we're collecting the belongings... then we ask her, [patient's wife] 'What do you want us to collect? Communications and policy is what you have to follow here. (#04; RPN)

These quotes indicate that the time surrounding patients' deaths can be very busy as nurses are engaged in many tasks caring for the patient, supporting the family and following organizational policies and procedures. In the moment, engaging in these practicalities may be in the foreground of nurses' experiences. Nurses' personal experience of the patient's death, including their emotional reactions, will be described in the following section.

Personally Experiencing Patients' Deaths: 'I'm a human being too'

As participants described their nursing activities, a more personal aspect of their experience pertaining to their comfort and values about dying and death and emotional reactions during the experience emerged. These intrapersonal themes related to who the nurse was as a person and were influenced by many factors including nurses' past death experiences, their values, beliefs and culture. The following section will describe the nurses' comfort with dying and death, the sense of relief that accompanied patients' deaths in CCC and their emotional reactions during and after the experience.

Being Comfortable with Death: ‘I’m just not at that point yet’

Participants often discussed their level of comfort during their experience of caring for a dying patient or a patient after death. Participants tied their comfort to their age and past experiences with death. One participant richly described the evolution of her feelings and comfort about dying over her career:

What clouded my feelings about death and dying early on in my career was having to sort through my feelings about how I felt about dying. When you start as a nurse...you’re not thinking about dying. You almost have to come to terms with what you think of as a good death. You think about what you would want if you were dying. And that kind of helped me sort out, ‘Ok, this is, this is what we are going to aim for.’ (#02; RN/ Nurse Leader)

In general, more experiences with death both as a nurse and in one’s personal life lead to increased comfort providing care to patients and families. This was evident in comparing novice and experienced participants’ experiences and when participants reflected back over their own careers. This indicates that past experiences and personal comfort are important for nurses as they develop palliative and EOL care competencies.

Novice and younger nurses and those without past experience with death outside of nursing were more likely to perceive their early experiences of patient death as uncomfortable and challenging. One participant described how she felt as she provided after death care independently for the first time:

I don’t know how I felt to tell you the truth, I didn’t feel right, that’s for sure. Being around death is tough, it’s just a weird sort of eerie...a pit in my stomach. (#08; RPN)

When this participant contemplated her values about her own death, further discomfort was evident:

I'm still uncomfortable with death or the thought of people close to me dying. It's a little easier to deal with now but I still don't have that comfort level yet of people that are like, 'I want this, I don't want to be here, don't do this.' I'm not at that point yet. (#08; RPN)

This participant compared herself to other nurses who were more comfortable and as she understood it, this comfort will come with time. Another participant had experienced two deaths in CCC, both of which occurred while she was off shift. She was uncomfortable about the idea of being the primary nurse when a patient dies as she said, "I still haven't had one [a patient death] first hand, like I haven't been on shift, thankfully (knocking on table)" (#07; RPN). This participant's gesture of 'knocking on wood' and hoping that she would not have to be the nurse overseeing care of a deceased patient illustrates her discomfort with caring for dying patients.

In direct contrast to these examples, a nurse with more years of work experience and personal experience of a parent dying alluded to her comfort caring for dying patients:

I went with this whole thing with my own mother cause she died of cancer...it doesn't bother me to be with people when that happens cause I've been there (#06; RPN)

Having 'been there' and having tangible experience with death facilitated nurses' experiences when patients died. Participants with more death experiences were more likely to describe how they enjoyed providing EOL care and found it rewarding.

Another facet of comfort emerged when exploring how nurses acknowledge their patients' deaths. More experienced nurses often described attending memorial services or funerals for patients. When novice participants were asked how they felt about attending formal services one replied:

Going to something like that, no. I wouldn't, I truly don't even want to do something like that for someone I knew in my personal life. I'm thoroughly that uncomfortable with it, I do not like it... So for a stranger for me, no (#07; RPN)

This quote demonstrates the significant unease that this participant feels when contemplating attending a funeral. This participant's language also firmly separated her personal life from a 'stranger's death.' Another novice nurse echoed this sentiment when she emphasized her conscious effort to leave work relationships at work and therefore would not attend a service. This discomfort may have led these participants to delineate concrete boundaries by associating patient's death as death of a stranger. This may reflect their understanding of what is an appropriate way to acknowledge a patient's death as a nurse. In more experienced participants, this separation was not evident. One participant with more than 15 years of nursing experience instead described that over time, nurses learn to 'fluidly' navigate boundaries of remaining professional while showing caring and respect for patients and families (#05; RN).

Feeling Relieved: 'Maybe it was for the best'

Despite sadness or other negative emotions, a sense of relief was commonly described by participants when they shared memorable patient death experiences. This relief was a consequence of how participants had come to define quality-of-life. This definition also came with time, experience, mentorship from other nurses and from

working with the patient population in CCC. Despite this, even novice nurses began to reflect their new understandings and values in their early death experiences. All participants arrived at and described a sense of relief accompanying the patient's death, regardless of whether it was perceived as a positive or negative experience. An example of this relief accompanied a very distressing patient death experience for one nurse who exclaimed, "I felt really, he is out of that struggle. Like a deep sigh. I felt relieved. I said ok, so he has no pain anymore. He's gone, he's gone" (#01; RPN).

Participants' descriptions often connected their sense of relief to identifying suffering with the patient's disease process further supporting the importance of understanding the context when exploring nurses' experiences. Many participants depicted the hard reality that death was often a good outcome for their patient. One nurse vividly captured this and her patient's decline over time:

Given the nature of her disease [MS] and what she had to endure over the last 20 or 30 years of...slowly, kind of melting away and not being able to do or communicate things and having to live in a place that's not her home and sleep in a bed that's not her bed, all of those things that we all take for granted. It's kind of sad to say but I think it's better for her to be where she is rather than to continue to be here to go through all of that. (#05; RN)

Another participant arrived at this understanding retrospectively as she recalled her first experience of caring for a patient after their death:

The patient didn't really have family involved in their life...I felt like it was better for him to pass cause he didn't really have any quality-of-life...I feel like sometimes when that happens [death] to a patient that's in a very tough situation, it's maybe just better for them to pass cause I think that's what the patient may have wanted...overall it was for the best. I don't come to that conclusion right away when I'm in the situation. But when you think about it later on, you're like, 'oh maybe it was for the best.' (#08, RPN)

The types of illnesses that patients die from in CCC support nurses' to value 'quality over quantity' (#04; RPN) and in turn, they are more likely to experience relief when a patient dies.

Emotionally Responding to Patients' Deaths: 'I was shattered'

Despite the nurses' experience-level and comfort with death, many participants described the difficulty and sadness that accompanied the death of patients. Words used by participants included 'sadness', 'loss', 'difficult', 'hard', 'tough' or 'upsetting'. Several participants displayed sadness by crying as they recounted their experience during the interview. One participant described that it feels similar to the death of a family member (#05; RN) and another depicted the potential extent of emotional upset related to patient death as:

And it was nice that I wasn't his nurse, because I was really shattered, I was shattered. I am a human being as well... A nurse, a mother, a daughter and a human being too. (#01; RPN)

This quote alludes to a tension between the role of the nurse and the personal connections and feelings of loss that can accompany a patient's death. This participant emphasized the death of her patient as a human experience.

Participants' reacted emotionally to different parts of the experience and described individual coping strategies. Some participants reported becoming teary or crying at the time of incident, while others processed their emotions away from work. Some participants attributed their sadness to feeling empathy for the patient's family while others felt sad because they lost a patient with whom they had a special relationship. Death incidents were described as more sad or negative when

they were unexpected, when the nurse perceived the patient suffered or they died alone, or when the nurse was worried about the family.

Expression of emotions differed among participants. One novice participant spoke about the uncertainty about what emotions are appropriate to show as a nurse. Part of this nurse's experience was 'figuring out' and learning about how a nurse should express emotions when a patient dies:

There's no written rules on how you're supposed to feel or how you react after someone passes away... Watching other nurses and seeing more senior nurses deal with family and their interactions and how they were so sincere about their emotions and stuff, it helped me. Ok it's not bad to sort of feel what the family is feeling. (#08; RPN)

A second participant questioned nurses' regulation of their emotions and wondered if she was so emotional over her patient's death because of having less experience:

Nobody else took it as hard as me. Because, emotionally, I felt like I'm not as strong as my other colleagues. Maybe they are more professional than me, they have been nursing for so long. And I'm just 6 years... Maybe they're controlling their emotions. (#01; RPN)

Both male participants referenced 'being a guy' or 'it's a guy thing' when describing emotional responses to patients' deaths or their perceptions of their colleagues' expectations of their emotions as male nurses.

The emotions accompanying a patient's death, particularly negative experiences, were described by participants as private and many participants desired to cope with the emotions independently. This is captured by one participant when she said, "Oh no, I don't want to talk in detail about the ones that have really troubled me because I'm trying to deal with it myself" (#02; RN/Nurse Leader).

Loss and grieving.

At times, the sadness or difficulty that accompanied a patient's death was described as being a loss or leading to grieving. Grieving was seen as a normal reaction to a patient's death in CCC, however a more negatively perceived experience may inhibit and prolong the process:

You can move into grieving, it helps people to proceed to grieve rather than to be angry...because they think something happened that was wrong...they sometimes cannot progress through the grieving process. (#02; RN/Nurse Leader)

Like other emotional responses, grief was seen as a private journey for the nurse to move through independently, without support from the organization or unit leadership as one participant described, "I think the way people grieve is a personal thing perhaps and we just all deal with it our own way right?" (#06; RPN). This indicates that formal grief support from the organization or in a group setting may be uncomfortable for some nurses in CCC.

Several participants described the type of internal work that is required by nurses when they grieve a patient's death. One participant described the importance of:

Reflecting back on your interactions with that person and what you appreciated about them, and what you're going to miss. That's kind of the internal, what you do to help you through your grieving is you go through that. (#02; RN/ Nurse Leader)

Loss could also be felt at the unit level. One novice participant described the sense of loss that she felt when one patient died on the unit, "She was there for years...and all the nurses loved her, so it was like a sad kind of...they lost, you could feel the loss on the floor. People were upset about it" (#07; RPN). Patients become a part of the fabric of the unit over years and their death leads to a feeling of loss for the whole unit.

Seeking Resolution in the Experience: ‘It was a good resolution’

Through participants’ detailed descriptions of critical experiences and their perceptions of these incidents, a theme of *seeking resolution* emerged. The nurse had no concerns about the patient’s dying experience or the family’s reaction and ability to cope. They felt able to fulfill the multiple aspects of their role and the experience aligned with their values, emotions and comfort. Early conceptions for this theme arose from one participant’s description of a positive experience in which she supported a daughter to provide after death care to her mother:

She [the patient] was lovely but she suffered...But when she died, her daughter came in and her daughter asked me if she could wash her mom. And so with her, we prepped her, we washed her. She did it so tenderly, so nicely...it was such a loving thing that she could do for her mom and for her to feel that it was done right. And it just felt like a very therapeutic thing, for her and for me...It was in the evening so it was quiet on the unit ...so it was nice to be able to support that. That’s what it felt like, very comforting very loving. It was a good resolution. (#02; RN/Nurse Leader)

In this experience, the nurse found an overall sense of contentment in the experience.

First, the patient was relieved from suffering with death. The nurse felt able to support the patient’s daughter to fulfill her wishes. At the time of the incident, the often busy unit was calm so the nurse could take this time. This understanding of finding resolution shows how closely nurses’ experiences are related to their perceptions of the patient and family’s experience.

Another perspective on finding resolution came from a nursing leader who described an experience in which she supported the unit nurses to work with a struggling family:

Over time you kind of watch the wife come to understand that we were doing the best we could and we came to understand her better, and then ultimately the husband died. All of that was worth it...all the effort that she [the nurse] put into establishing that relationship led to this end, which was a peaceful death and the wife is thankful for the care that the patient received. (#03; Nurse Leader)

Despite the initial conflict, the team and family came together and the patient was perceived to have had a peaceful death. Incidents with a ‘good resolution’ carried the sentiment that ‘everything went the way it should’ or ‘it all worked out in the end.’ A feeling of resolution could be used to understand and illustrate all of the positive incidents collected in this study. Achieving this feeling of resolution could be facilitated or impeded by nurses’ perceptions of support or the way that the patient’s death was acknowledged on the unit.

Experiencing Conflict and No Resolution

In contrast to finding resolution, several negative incidents illustrated conflict within the nurses’ experience. Examples of conflict included when care decisions were made for the patient that conflicted with the nurses’ values or when the patient died unexpectedly from a preventable cause. Participants used words such as ‘undigested’ ‘conflict’ and ‘unable to register’ and this conveyed a poor resolution of the nurses’ overall experience.

One participant experienced conflict because she felt that she had no voice as a nurse when she believed a care decision led to a patient’s suffering. She expressed:

He became palliative and food was stopped. That was a conflict with my values and I fought myself every single day. But being a nurse, I cannot be judgemental. I cannot step in on somebody else’s decisions. The one thing that sticks in my mind, I might need counselling for it, if he was able to make his own decision, I don’t think he would make this decision for himself...I couldn’t register it, I couldn’t register it...We are nurses and we just pass by, we cannot say anything to anybody. We

don't want to impose our decision on them... We just follow the instructions. (#01; RPN)

One consequence of a poor resolution was that the distress and negative emotions related to the experience stay with the nurses over long periods of time. One participant reflected, "There is always deaths like that, there's some, they stay with you longer. They're harder for you, you do a lot of soul-searching, I think the problem would be if, if you thought you could have done things differently" (#02; RN/Nurse Leader). This unresolved feeling led to an overall negative perception of the experience and at times participants reflected about being able to change the outcome for the patient, family or themselves.

Integrating Professional and Personal Experiences: 'Applying what you learn in your nursing life into your personal life and vice versa'

The role-related and personal experiences of each critical incident influenced one another over time to shape nurses' EOL care practices and their attitudes towards dying and death. Various factors such as unit culture, nurses' past experiences with death and years of experience played into this dynamic. The result of this mutual feedback was an evolution in the nurse and his/her experiences over time. This finding moved beyond the isolated critical incidents from nurses' practice and created a sense of continuity across nurses' experiences with death.

Participants demonstrated integration when they spoke about what they took away from each incident and how it shaped their life and future practice. One participant spoke to this growth when she said, "And that's where it's changed me as a person, since I've been working [as a nurse]. Now, I'm looking for quality [of life], not quantity" (#04;

RPN). This participant came to value quality-of-life over years of life both for her patients and for herself. A second participant reflected back to the start of her career and providing EOL care:

They [patients' deaths] absolutely shape your practice. It makes you more caring. It makes you understand the situation better, you know where people are heading. When I first was a new grad and practicing, I was so upset with dying and the thought of dying. It actually makes you form your own attitudes towards dying. Because you never consider for yourself, when you start you're 23 and you don't think about dying, so how can you help someone through that experience? As you get older and mature, you have more experiences, you know what you can do to make someone like comfortable and how you can talk to families and help them and support them through the process.
(#02; RN/Nurse Leader)

This quote embodies this theme because it shows both how the participant's practice and ability to care for patients and families improved while, at the same time, she developed her own values towards dying.

Participants went on to describe how they applied learnings from their death experiences of patients outside their nursing practice. Many participants described how caring for patients in CCC influenced their wishes for their own death. One participant described her realization of the impermanence of life and how she tried to impart that to her children:

I don't trust in life anymore, everybody has to go. Before I never thought like that. Now I think, 'Oh, sometime, everybody has to go.' I really want my children to know that everybody has to go so they are not shocked if something happens to me...I even tell my 10 year old that everybody has to go. Because I want them to get on with their life
(#01; RPN)

Another participant anticipated her parents' deaths and reflected on her increased comfort talking to her parents about their preferences:

I'm heading down that road with my parents. One is in long term care and one's wanting to join the other spouse there...so we've been talking about funerals and planning. I said to my dad, 'You kind of know what music you want, but if you don't tell me it's not going to happen. Not to be morbid but let's talk about this and plan it out.' So we've had some conversations and planned for the funeral. (#02; RN/Nurse Leader)

One nurse integrated personhood into her role as a nurse supporting family members of dying patients after one critical experience of patient death:

I just look at each person and each family differently. How can I be supportive? What is my role besides just nursing? How can I be towards the family, to realize their experience, talk to them and help them open up to us as staff. So they don't just see me as, 'Oh she's his or her nurse today.' No, I'm that person that you can talk to if you need. And that's where I am now when they [patients] are at the end of life. I'm trying to be like, 'I'm there for you too' (#04; RPN)

Many rich examples indicated that nurses' past death experiences are important in shaping their future practice experiences, personal values and attitudes. The differences between novice and experienced nurses' experiences were complex and multi-factorial and could be understood by looking beyond nurses' clinical competence to see the influence of nurses' comfort, values and past experiences.

Supporting One Another in a Culture of Acknowledging Patients' Deaths and Nurses' Experiences: 'They expect us just to take it, the nursing profession is like that'

Most participants felt that little was done by the organization and leadership to support nurses when patients died. In addition, a common perception of participants was that 'support' was an emotional support or group activity. This is expressed by one participant who said, "I think a lot of people like to grieve independently...I don't know that group meetings would actually be beneficial for people... I think that people grieve

in their own way...you can't make me grieve!" (#02; RN/Nurse Leader). As a result, some participants felt that this form of support would not be beneficial because of individual and private grieving processes.

Similarly, one participant discussed the discomfort with and slow acceptance among nurses of 'touchy-feely' type initiatives within the organization such as mindfulness (#03; Nurse Leader). Besides more novice participants desiring in-service education about skills relating to EOL care, many participants felt that formal support was unnecessary and would not be feasible in the busy CCC setting. These initial findings spurred significant reflection during data collection and analysis as it became clear that the word support was not adequate to describe what would benefit or be meaningful to participants.

What was uncovered instead was a complex health care and nursing culture which surrounds death in CCC. Rather than support as it was understood by the participants, nurses described a culture in which death was not talked about. They desired a unit dynamic and processes which showed respect to patients after their deaths and which acknowledged the family and nurse experience. Three sub-themes relating to unit culture and new understanding of support will now be described.

Communicating About Death: 'It's this unspoken kind of thing'

Patients' deaths and opportunities for support were rarely discussed among nurses and unit leadership. Beyond brief mention of a unit death during team huddles on the shift of the patient's death, both direct care nurses and nurses in leadership positions noted a gap in communication about patient death. Due to the nature of nurses' shift work, a

patient's death could be 'missed' (#03; Nurse Leader) and the short window for discussion or support passed. This lack of communication was mutual in that participants described not asking for additional support, while also explaining that it was also never offered to them. One participant reflected about the absence of discourse about death and support:

We've never asked, they've never asked, it's kind of like this unspoken kind of thing. I don't know if it's unspoken because it doesn't matter to anybody...if it's unspoken because people are afraid to open up that can of worms, whether it's just people have their own way of grieving and it's not really an issue for people...it's a pretty important area that we haven't really done a lot of talking about (#03, Nurse Leader)

This silence may reflect nurses' desire for privacy or their lack of awareness of resources. It may also relate to an accepted norm in the nursing profession as one participant described:

Unfortunately, here we don't get any support when somebody dies. They expect us to just take it...Carry on. The nursing profession is like that...this is the professional demand. How do I explain it to you? This happens. We expect that. This is our job. (#01; RPN)

This quote indicates that direct-care nurses and nursing leadership may subscribe to an idea that because death is an inevitable part of nurses' work, that it should not require additional support.

Consequences of this silence may be that nurses feel expected to cope independently or they may simply be unaware of options for additional support. As one example, one participant confided in the investigator that this was her first time sharing her distressing experience despite having a morally conflicting experience and continuing to experience negative emotions in the year since the patient's death. A novice nurse

described the lack of dialogue and poor awareness of support resources when she described:

I didn't seek out any [support] and I honestly don't know if there's any. I never hear it mentioned if there's resources for nurses, for someone to speak with if they're having difficulty with a passing of a patient...I don't know if those resources exist, I'm sure they probably do, I would hope they do. (#08; RPN)

Although participants felt that formal support is not always feasible or required for every patient death, they felt that there should be an openness and opportunity to have these discussions. One participant described that having a small symbolic acknowledgement of a patient's death on the unit, such as an electric candle being lit, could serve as such an opportunity, "And it creates, even a conversational opportunity to say, 'Oh, who died?'...and then the conversation is there and everybody gets an opportunity to talk about it. So even as simple as that, would be good enough" (#05; RN).

Respecting Death and Acknowledging Each Other's Experiences

Respect and acknowledgement were persistent themes that included recognizing the deceased patient, the family's and nurses' experiences. Nurses desired that this respect and acknowledgement was embedded in unit processes and shown by all unit members, including other nurses and staff, family members and unit leadership.

Respecting the life and death of the person: 'They weren't just a patient in a bed.'

Participants felt that unit processes such as hasty room cleaning, new patient admission after a patient's death and the absence of team dialogue about the death neglected to show respect to the patient as a person who lived and died in CCC. One

participant cried when recalling a lack of respect that was shown to the family's experience after a patient died:

I find the turnover is just so quick...like it's, 'Get somebody else in the room,' it's just awful...just that feeling, it's almost in a sense of that person meant nothing because the room is just cleared out so quick, like why can't they wait a little bit longer? (#06; RPN)

A second participant verified this feeling and described how the unit moves on after a death. Both participants alluded to how these practices devalued the person's life in CCC and following their death, it was as if they were forgotten or not important:

I come in and I'm like, 'oh, what happened to this person?' They passed away two days ago and I was off for 3 days. That's odd too, all of the sudden a name is off the board and they're gone and you didn't see them at all...you come back and they're gone...not that they didn't exist but, they're just gone. (#08; RPN)

This participant added the importance of respecting the person behind the patient. She described what she took away from the experience of gathering the patient's belongings:

You're packing up someone's belongings and you're going through their stuff. And you're like, 'Oh this is what he looked like and he had all these CDs and this is what he used to listen to.' You get a respect for someone's life and they lived outside of here...they weren't just a patient in a bed, they had a full life outside of this place. (#08; RPN)

Four participants described attending patients' funerals or memorial services in order to pay respect to the patient and their family. Some participants regretted not having this opportunity when there was no service, they could not attend because of work schedules or when they found out about the patient's death too late. The participants appreciated when a picture was placed on an existing unit memorial board or when families returned to visit the unit. These gestures served as

opportunity to remember the patient. Unfortunately, opportunities like these were inconsistent and infrequent.

Acknowledging the nurse’s experience: ‘They take us as a caregiver.’

Participants’ benefitted when other nurses, unit leadership and patients’ families were sensitive to their experience. One participant described an experience when she felt the unit nurses were insensitive to her when she experienced her first death. This led to her describing her experience of this patient’s death as ‘awful’. Participants discussed the benefit of receiving feedback from families indicating that they were happy with the care provided to the patient. This feedback was sought in printed obituaries and was at times received in-person when a nurse attended the funeral or the family visited the unit:

Unless you see a death announcement and they actually put something in to thank the staff, and I’m thinking, ‘ok, that’s nice’, but sometimes you don’t see that. And I don’t know if it’s because families don’t think that staff look. To me, it makes me feel comforted if I think the family was happy with the care...it’s just that they, you’re not looking for praise. You’re looking for that they felt like that we did do a good job. (#02; RN/Nurse Leader)

One participant lit up when she recalled the welcome she and her family received when she attended a patient’s funeral, “And I went there, and his wife introduced me to everybody...and they were so nice, they met me so nicely...they gave me so much respect, they introduced me” (#01; RPN).

This mutual respect for the patient’s life and death and for the nurses’ role in providing a good EOL experience was a key factor that influenced nurses’ on-going experience after a patient died in CCC. One poignant quote captured how the

culture and processes of CCC often fail to recognize the relationships and experiences of nurses when a patient dies, “They take us as a caregiver. And when somebody dies, they take away their stuff, they take away their papers but they don’t remember they are leaving the memories with us” (#01; RPN).

Feeling Understood: ‘They understand me better than anybody else’

The study participants recognized that experiencing patient death was an inevitable part of their role. The most meaningful and helpful form of support described by participants came from their nursing colleagues. Other unit nurses also knew the patient and could empathize with one another’s experience. All participants acknowledged the challenge of finding this understanding in other friends or family members. They also did not want to burden them with sadness when talking about a patient’s death. One participant described these different factors:

They [family members or friends] don’t want to hear the sad ones [stories]. And they don’t understand either, they don’t understand what end-stage COPD is, right? They just don’t get it... You want someone to acknowledge you and understand it from a nursing perspective. (#07; RPN)

To one extreme, one participant identified that she would prefer to stay and work after having a challenging experience with patient death rather than take a vacation because she would need her colleagues’ support and understanding to get through the experience.

Another layer to seeking understanding was that they preferred that this support came from someone ‘on the same playing field’ (#05; RN), as opposed to a more formal type of support from someone like a manager. A further benefit of collegial support was that it could be on-the-go in a busy environment such as recognizing when a colleague

needed a quick break or changing their patient assignment. The subtlety of this support is necessary in the busy CCC environment. One participant described the nature of collegial support:

I think it is what it's supposed to be. If you're getting attached to that person more, they will try to help you more... I don't have to speak up, they will see and they will reach out...I know a couple situations where we just said, 'Ok, today I will do it, we will switch the patient.' That way she doesn't have to deal with that all the time. That's how we as a team work together. (#04; RPN)

In general, the unit nurses felt very supported by their colleagues. In contrast to this, one male participant felt that he was not emotionally supported by his colleagues or included in their support of one another. He felt that his colleagues' perceived that he did not share the same feelings of upset in response to a patient's death or desire for support because he was male. Similarly, a participant who floated to different units felt that she was not always a part of this network of support. Feeling understood, particularly by other nursing colleagues, was an important way that nurses' felt supported when patients died in their practice.

Summary of Findings

Within CCC, five themes emerged which described nurses' experiences with death, how nurses acknowledge their patients' deaths, and their perceptions of support. Nurses' described their experience in terms of their role as a nurse, and the impact of these experiences as a human being. Participants described their key nursing activities as keeping the patient comfortable, preparing and supporting the patient's family and following hospital procedures. Alongside their role, participants described their personal experience of the incident and this encompassed their values, emotions, and their sense of

comfort during the experience. Factors such as years of experience and past death experiences led to differences within the themes, particularly between novice and more experienced nurses. A sense of resolution resulted when they were able to fulfill their roles and there was congruence between their personal values and comfort with the patient's death. An integration of professional and personal death experiences in a journey over time was elucidated as participants described how early death experiences shaped their values and attitudes about death, future nursing practice, and awareness and preparation for future death experiences.

Nurses' experiences were influenced by the culture of the unit, which CCC, the organization and the unit which influenced how the patient's death and nurses' experiences were acknowledged and participants' perceptions of feeling supported. Participants felt that death was not spoken about and that unit processes did not support them to show respect for the person who died and did not acknowledge the family's or nurse's experience of the death. Nurses in CCC informally supported one another and felt that their colleagues understood and could support them best.

CHAPTER 5

DISCUSSION

The findings from this study advance current knowledge about nurses' experiences when their patients die in continuing care settings like CCC in four key areas; (1) supporting nurses within an organizational culture that acknowledges death; (2) unique experiences of novice and experienced nurses; (3) influences of gender on perceptions and experiences of collegial support; and (4) the influence of relational boundaries in continuing care settings and EOL care. These areas were selected for discussion in this chapter because they required further exploration to help understand and explain the findings more fully. As such, these key areas were expanded upon in light of previous literature to advance our knowledge in a more comprehensive manner.

Supporting Nurses within an Organizational Culture that Acknowledges Death

An important understanding that arose from this research was that support goes beyond isolated interventions to help nurses and care providers cope when patients die. Rather, it is a feeling of being supported which can result from subtle organizational attitudes which are embedded in unit dynamics and processes. This interpretation emerged from findings that despite participants perceiving little support when patients died, several nurses expressed that formal support would not benefit them. Alternatively, nurses' desire for open communication about patients' deaths, understanding and acknowledgement of their experiences and showing respect to deceased patients and their families permeated the interviews in this study.

A recent study which explored carer providers' grief support needs in LTC recognized that the foundation of supporting staff in their patient death experiences was fostering an organizational culture which openly accepts that many patients die and that their deaths have personal implications for staff members (Marcella & Kelley, 2015). This may mean that the first step towards supporting nurses through patient death experiences in CCC is to recognize that CCC is a significant setting where many patients die and that patients' deaths are important experiences for nurse that requires support (Marcella & Kelley, 2015). Therefore, meaningful ways of supporting nurses may include embedding intentional and thoughtful activities and gestures into everyday practice such as creating and maintaining memory walls, creating opportunities for and encouraging staff to discuss and reminisce about patients after their deaths, having a formal strategy to inform staff of patients' deaths, acknowledging that their deaths can lead to feelings of loss for nurses and unit leadership informally checking in with their staff after patients die (Marcella & Kelley, 2015). These actions and attitudes may improve nurses' perceptions of support and their subsequent well-being more than implementation of additional support interventions.

In the nursing literature, organizational culture is often referred to as the nursing practice environment (Sleutel, 2000). A healthy practice environment is a setting in which nurses feel able to provide satisfying and quality care to patients, while also meeting their own personal needs (Kramer & Schmalenberg, 2005). When reflecting on the findings of this study, barriers for nurses experiencing resolution following a patient's death, such as a lack of open communication about the patient after their death or quickly filling the bed

with a new patient, may lead nurses to feel that quality care was not provided to the patient and family. They may also feel that their own needs of acknowledging a patient's death were unmet. The dissonance experienced by some participants of this study may be symptoms of an environment which denies the personal experiences and needs of nurses when patients die.

Comprehensive support interventions such as Comfort Care Rounds, which include education, peer support and debriefing, cannot meet the needs of all staff in a particular setting (Wickson-Griffiths et al., 2015). As participants in the current study described, everybody grieves differently and some parts of their experience are private. The nature of busy healthcare environments is that nurses may not be able to attend such activities even when they are working (Maitland et al., 2012; Wickson-Griffiths et al., 2015). This understanding challenges organizations to explore the implications of everyday unit processes on the well-being of nurses.

Quested and Rudge (2003) conducted a discourse analysis on the after death care procedures of an acute care hospital in Australia, which explored how organizational and health care cultures direct nurses' practice when patients die. They found that the procedures did not include patients' or families' preferences for care of the patient's body after death but projected the values and culture of the institution. The language gradually depersonalized the deceased person by using terms to refer to them as 'the body' and 'the case.' The nursing actions appeared to first remove the layers of the person, for example stripping of their clothing and jewellery. Nurses then were directed to add layers to hide the body by shrouding, placing them in a body bag and transferring them to the morgue

(Quested & Rudge, 2003). They found that these procedures reflected the invisibility and hidden nature of death in Western culture.

Cowie (2012) reviewed an organizational after death care policy and engaged multiple stakeholders through the lens of practice development to question taken-for-granted care practices of patients following death in a Canadian CCC and rehabilitation hospital. Cowie uncovered that care providers experienced moral distress when placing toe tags on and shrouding the patient whom they cared for like family. Nurses and PSWs felt they were obliged to follow these practices despite disagreeing with them. Funeral home staff were uncomfortable with current hospital practices which mandated transfer of the person's body to the funeral home through the back service doors and passing by garbage dumpsters. This policy thus compromised their ability to provide person-centred care in CCC and led to distress for people caring for the person after their death (Cowie, 2012). Findings from these works demonstrate how practices which reflect the culture of hidden death in health care can lead to negative experiences for care providers'.

An additional benefit of embedding support and acknowledgment of nurses in everyday unit processes is that it may not require additional human or financial resources (Marcella & Kelley, 2015). Unit managers and leadership can role-model an open and acknowledging culture surrounding patients' deaths by recognizing the potential impact that caring for dying patients can have on care providers (Anderson et al., 2015; Marcella & Kelley, 2015; Wilson, 2014) such as by taking a moment to sit with a nurse and acknowledge their feelings (Gannon & Dowling, 2011). Other strategies can include recognizing the care demands of dying patients and their families and reflecting this in

staffing levels, scheduling and how patient are assigned (Katz et al., 2001; Marcella & Kelley, 2015). Simple and creative approaches can take formal support of nurses beyond education and group debriefing. The participants in this study suggested many simple ways of acknowledging patients' death such as lighting a candle in the nursing station when patients die or placing a picture of the person on the memory board. Setting leaders should engage their staff in identifying specific rituals or activities that will be meaningful for them (Marcella & Kelley, 2015).

Experiencing Patient Death as a Novice and Experienced Nurse

In this study of nurses' experiences of patients' deaths, variations were found within the themes which were commonly attributed by participants to their years of nursing experience. For example, novice nurses expressed discomfort with many aspects of the experience such as providing emotional support to families, being around dying and death, acknowledging patients' deaths by attending funerals and 'knowing what to do' when it came to caring for the patient's body after death. This pattern highlighted that nurses' age and years of nursing experience influenced whether they had past death experiences on which to draw in the recalled memorable incident.

In the past literature, differences in nurses and other care providers' experiences were described in two survey studies which found that care providers with *more* years of experience were *more* likely to exhibit symptoms of grief or be more negatively affected by patient death (Rickerson et al. 2005; O'Hara et al., 1996). These findings were attributed to an accumulation of negative responses to patients' deaths related to working in a setting in which patients commonly die and having little support or personal coping

resources (Rickerson et al., 2005; O'Hara et al., 1996). These findings might be explained by the related concepts of burnout (Pines & Aronson, 1988), compassion fatigue (Figley, 1995; Figley, 2002) and/or cumulative grief (Marino, 1998). Burnout is a state of total exhaustion which results from being involved in emotionally demanding situations over long periods of time (Pines & Aronson, 1988). A form of burnout, compassion fatigue, is a state of tension and reduced capacity to be empathetic to others as a result of bearing witness to others' suffering (Figley, 2002). Finally, nurses may experience bereavement overload or cumulative grief when they have inadequate time or resources to completely grieve one patient's death before another occurs (Marino, 1998). A common theme among these concepts is that they result from continued emotional involvement, exposure to suffering and feelings of grief over time which indicates that nurses with greater years of experience are at greater risk of experiencing these phenomena.

In the current study, qualitative differences in participants' experience were that novice nurses experienced general discomfort caring for patients at EOL including being less confident emotionally supporting patients' family members, being uncertain of how they felt during the experience, feeling uncertain about expressing their emotions and being less comfortable being around and talking about death. These findings may indicate that in addition to nurses experiencing different magnitudes of negativity or grief based on their years of nursing experience (Rickerson et al., 2005; O'Hara et al., 1996), the experiences of nurses with less and more years of experience may be qualitatively unique.

Another way to understand the uniqueness of nurses' experiences may be to explore the kinds of knowledge which inform their practice and perceptions of providing

EOL care. Using the seminal work by Carper (1978), participants' perceptions of the factors which influenced their experiences in this study were largely based on personal, aesthetic and moral knowledge. The value that nurses' place of these patterns of knowing and their ability to draw on them in EOL practice experiences may vary over nurses' careers. For example, nurses who have cared for more dying patients and their families over longer careers and those who have experienced personal loss, are likely to have more personal knowledge to draw on when providing care to patients and families.

Competency and comfort providing EOL nursing care may particularly depend upon personal and aesthetic knowledge that nurses develop through life experience as opposed to traditional empirical knowledge. This could mean that novice and experienced nurses require different content and approaches to education to prepare and support them in their experiences of patient deaths. For example, hands-on experience caring for dying patients and life experiences may be necessary for new nurses to develop the personal and aesthetic knowledge required to provide EOL care with confidence and competence.

Although the experiences of novice and proficient nurses' may be qualitatively different, this study's theme of *integrating professional and personal experiences* supports the abstraction that participants were experiencing different points along the same journey of understanding how dying and death touches their lives. Several participants recalled how they felt about patients' deaths at the start of their career and how this had changed over time. Gerow and colleagues (2010) described a journey and growth of nurses' spiritual views relating to patient death experiences. Their spiritual beliefs, for example belief in an afterlife, were a significant part of nurses' coping when

patients died. As a result of caring for patients at EOL, nurses' spiritual beliefs deepened and significant death experiences changed who they were as human beings, beyond their professional identity as a nurse (Gerow et al., 2010). In the current study, a similar interrelationship of their personal and professional experiences resulted in an evolution of their comfort providing EOL care and values and attitudes towards dying and death. More experienced nurses can play an important role in providing mentorship, reassurance and wisdom to fledgling nurses by drawing on their personal and aesthetic knowledge (Anderson et al., 2015; Marcella & Kelley, 2015). Overall, this study supported that it is important to distinguish between neophyte and proficient nurses' experiences and this may influence the nature and content of education and support that nurses require.

The Influence of Gender on Nurses' Perceptions of Support

The finding that male nurses may feel excluded from the informal network of support among female nurse colleagues challenged the finding that most participants described a strong sense of collegial support when patients died. Only three of the seven main studies that informed the literature review of nurses' experiences of patient death in continuing care or acute care settings had male participants (Anderson et al., 2015; Gerow et al., 2010; O'Hara et al., 1996). These studies neither described nor attributed different experiences of support to nurses' gender. These perceptions may stem from a female-oriented culture in nursing and CCC. Therefore, it is important that organization leadership and female nursing colleagues recognize that male nurses may not perceive the same level of support. Intentional efforts to support male nurses based on evidence of

their support needs and preferences may be required to increase their sense of inclusion and their experiences when patients die.

Fisher (2003) used life course methodology to explore the lives and social structures which form male nurses' identity of masculinity. An important theme was the sense of isolation that many male nurses experience in their practice. The participants felt isolated from both the social activities of their female colleagues and from support from their non-nurse male peers because they were males in the nursing profession (Fisher, 2003). The participants perceived that their colleagues assumed that they would not want to partake in 'feminine' activities such as social gatherings. In addition, this study's participants described their own emotions as 'closed off' which further isolated them from emotional support from both male and female colleagues and peer. Fisher's (2003) work confirms that male nurses' feelings of isolation extend beyond clinical circumstances when patients die. Differences in emotional expression and assumptions made by female colleagues and leaders may unintentionally bar male nurses from experiences of informal social support or partaking in rituals when patients die, which is related to having a more negative experiences when patients die (O'Hara et al., 1996) and on-going emotional distress (Anderson et al., 2015).

Male nursing students and teachers in a Norway nursing program felt that their colleagues and superiors were unaccepting of their enactment of feminine nursing values such as caring (Soerlie, Talseth & Norberg, 1997). As a result, the participants felt excluded from traditional aspects of nursing and experienced internal conflict in their identity as a nurse (Soerlie et al., 1997). Nurses from the current study identified that

EOL care draws heavily on nursing values of caring when nurses protect the patient and prepare and support patients and family members and that it can be an emotional experience for nurses. Male nurses may feel conflicted providing this care and subsequently uncomfortable seeking emotional support from their colleagues (Fisher, 2003; Soerlie et al., 1997).

A study of male RNs in eastern Canada found that male nurses preferred to socialize with one another because they share similar hardships in a female-dominated environment (Evans & Frank, 2003). This makes sense in light of this study's findings that an important element of informal support is feeling understood. Less than 7% of regulated nurses in Ontario are male (CIHI, 2013). It is likely that an even smaller proportion of males work in settings such as CCC because they more often work in care settings which encourage masculine traits of strength, technical skills and autonomy such as critical care or emergency nursing (Evans, 1997). This suggests that male nurses in CCC may be at greater risk of feeling isolated and unsupported. This raises concerns about the potential impact of this lack of support on their experience and long term outcomes as a nurse in continuing care settings. Awareness of the potential for male nurses to feel excluded is important, and like novice nurses, they may require intentional and targeted support which considers their needs and preferences.

Relational Boundaries Between Nurses and Patients in End-of-Life Care

Among participants of this study, some participants expressed having a personal connection with their patients and while others were more intentional to separate their personal and professional relationship. A specific example included that two novice

participants expressed strong discomfort and needing to separate their personal and professional lives regarding the idea of attending patients' funerals. On the other hand, most other participants desired to attend patients' funerals when possible. This finding first suggests that nurse-patient relational boundaries may influence nurses' experiences when their patients die in CCC. It may also reflect that nurses may hold different definitions of relational boundaries in their practice and that this may be related to their years of nursing experience.

Gerow and her colleagues (2010) found that nurses intentionally compartmentalize their personal and professional experiences for two reasons: in order to remain professional and for self-protection. Boundaries acted as a curtain of protection, shielding nurses and patients from the vulnerability that accompanies end-of-life (Gerow et al., 2010). Being 'professional' was defined by nurses in another study as maintaining composure while providing care and being able to execute care expectations competently (Anderson et al., 2015). Similarly, the College of Nurses' of Ontario (CNO) emphasizes that boundaries are required in order to preserve therapeutic nurse-patient relationships, which center on the needs of the client (CNO, 2013). Boundaries employed for self-protection may be particularly important in settings in which patients die and nurses have long term relationships with patients. The different preferences of nurses related to attending patients' funerals in the current study may be evidence that novice nurses require more rigid boundaries to protect themselves from upset and discomfort. It may also reflect their socialization as new nurses, as they may perceive that it is unprofessional to attend patients' funerals.

The use and rationale for boundary utilization also depends on the clinical situation and the individual nurse (Lilibrige, Axford & Rowley, 2000). Gerow and colleagues (2010) described that the permeability of nurses' boundaries varies depending on where the nurse is on his or her life journey. Over time, nurses develop inner knowledge that grief can be a normal response to patients' deaths, which shows the caring relationship they developed for another person (Gerow et al. 2010). A naturalist inquiry study of RNs' perspectives of their scope of practice and use of boundaries found four ways that nurses live out boundaries in their nurse-client relationships: remaining in their comfort zone by focusing on tasks, moving into a safe territory that focuses on functional nursing roles, moving into a grey zone and finally, stepping over the line (Lilibrige et al., 2000). Nurses who were comfortable with their nursing knowledge, professional identity and clinical environment were able to move out of their comfort zone, fulfilling other roles such as collaboration and advocacy while staying within safe and professional boundaries (Lilibrige et al., 2000). These studies' findings support the interpretation that the novice nurses in this study may have relied upon boundaries to preserve a level of comfort in their early practice. Attending patients' funerals may be uncomfortable and upsetting for these nurses, which could have led to more negative perceptions of their experience. It is important that clinical leaders and educators have knowledge about how and why nurses' employ boundaries in EOL in order to prepare and support nurses when patients die in settings such as CCC.

The specific clinical circumstance of patients nearing EOL may necessitate expanding boundaries that might otherwise exist. For example, Gerow and colleagues

(2010) found that RNs experienced special connections with patients and families when they accompanied them in the universally human experience towards death. This connection was described as transcending traditional professional relationships because the nurse also benefitted from emotional support and validation he or she received from the relationships with patients and families (Gerow et al., 2010). Gannon and Dowling (2011) also found that nurses in LTC described a unique emotional connection in caregiver-patient relationships surrounding a patient's death. This too was found in the present study, when nurses described going above and beyond for their patients, including one nurse who reflected on being 'more than a nurse' when providing support to patients' family members.

Many studies have shown that nurses believe that developing personal relationships and attachment with patients is fundamental to providing quality EOL care (Gannon & Dowling, 2011; Katz et al., 2001; Marcella & Kelley, 2015; O'Hara et al., 1996; Wilson & Daley, 1998). Tension may result when nurses use boundaries for self-protection and professionalism when providing EOL care, as it may act as a barrier to developing the nature of relationships that nurses see as important in EOL care. This conflict may continue following the patient's death if nurses experience loss, sadness or grief (Gerow et al., 2010; O'Hara, 1996). Nurses may perceive these responses to patients' deaths as unprofessional (Gerow et al., 2015) leading to feelings of conflict, potentially inhibiting them from seeking informal or formal support. Defining boundaries in continuing care settings like CCC becomes more complex when patients approach

death and nurses, particularly in their early careers, may need guidance and support defining and maintaining these boundaries.

The discourse about boundaries that emerged from this study sheds light on the importance of understanding boundaries in EOL care, especially in continuing care settings like CCC. More experienced nurses may be better equipped to navigate the complexities of nurse-client relationships, however open discussion and group reflection about therapeutic boundaries may benefit all nurses in CCC. The example of attending funerals which prompted this discussion may in fact be a professional acknowledgement activity if the intention is to meet the needs of the patient's family (CNO, 2013). If attending funerals is seen as a therapeutic intervention, organizations could consider developing formal protocols to ensure an organizational or unit presence at patients' funerals or memorial services as part of the patient's care plan. Attending funerals may simultaneously help nurses to find resolution in their own experiences of loss, providing opportunities to pay respects to the patient and family. A gap in unit-based support and acknowledgement activities for nurses may be demonstrated if nurses are predominantly motivated to attend patients' funerals to meet their own needs.

Discussion Summary

The findings from this study enhance our understanding of nurses' experiences when patients die. This study built on recent findings from research in LTC that an open and acknowledging unit and organizational culture is an important foundation for supporting nurses when patients die (Marcella & Kelley, 2015). This study confirmed that past death experiences and years practicing nursing are key factors influencing nurses'

experiences and added a deeper qualitative understanding of how their experiences differ. The complexity of boundaries in nurse-patient relationships surrounding patients' deaths in continuing care settings was deepened. Finally, this study introduced how male nurses' experiences may be unique in their perceptions and experiences of support. These findings have implications for practice, education, policy and future research, and these will be explored in the next and final chapter.

CHAPTER 6

LIMITATIONS, IMPLICATIONS AND CONCLUSION

This chapter will describe the limitations of this study and how they may influence the interpretation and transferability of the findings. Following this, the implications of this research will be explored in relation to clinical practice, nursing education, policy and future research.

Study Limitations

Although a small sample may be appropriate for exploring common phenomenon in depth (Thorne, 2008), the composition of this small sample could have been optimized to more fully explore the phenomenon of nurses' experiences of patients' deaths in CCC. Five out of six of the direct-care nurses in the study were RPNs and no PSWs were included due to their recent addition to the care model on one of the CCC units. A more heterogeneous sample may have solidified the importance of the shared experiences and increased the transferability of the findings (Patton, 2015). It also may have facilitated identification of unique education and support needs of different care staff based on the nature and length of their educational backgrounds. In addition, both novice participants (1-5 years of nursing experience) had only been nursing for one year. Having novice or intermediate nurses with a wider range of experience may have enriched the findings with a deeper understanding of the progression of nurses' journeys with patient death. The contrast of nurses with one year's experience compared to nurses with six or more years may have led more to a dichotomy of experiences between novice and experienced nurses as opposed to a continuum. Barriers to recruiting a more diverse sample of participants in

this study included that less experienced nurses did not always meet the criteria of having cared for a patient at EOL and, as to be expected, some potential RN and novice participants declined to participate. Since these limitations could not be addressed in the current study, future research with a larger and more diverse sample of nurses in CCC may be required to confirm the findings from this study.

This study could not capture nurses who may have left or avoided working in continuing care settings related to not wanting to work with dying patients. Also, nurses with death anxiety or who did not feel comfortable recalling negative experiences were unlikely to agree to participate in this study. This may mean that the description of nurses' support needs and preferences and the subsequent recommendations made from this study may be inadequate to meet the needs of these nurses. Nurses who only work evening or night shifts were also not captured with recruitment strategies. They may have unique experiences when patients die related to lower numbers of staff working during these hours and fewer opportunities for education and support from unit leadership.

Finally, this study took place in one continuing care hospital in Southern Ontario. This threatens the transferability of the study's findings to other CCC care settings (Patton, 2015). As was learned in this study, the care setting's culture of recognizing and acknowledging deceased patients and the nurses' experiences was closely related to nurses' experiences of patient death. Culture in healthcare may vary considerably from organization to organization and even at the unit level (Scott, Mannion, Davies & Marshall, 2003). In addition, hospital-based CCC exists only in Ontario and Manitoba,

and therefore provincial differences in funding and care delivery may impact the transferability of these findings to other CCC hospitals outside of Ontario.

Implications for Practice

A fundamental finding from this research is the influence of organizational and unit cultures on nurses' experiences of patient death. Culture change in health care organizations is a complex concept that requires strong leadership, multiple strategies and time (Scott et al., 2003). Although an overall culture shift far exceeds the scope of implications of the results from this study, some strategies are recommended to address the findings of a gap in communication about dying and death in CCC, nurse's desire to show respect for the deceased person and their family and acknowledgement of nurses' experiences. Marcella and Kelley (2015) outlined several strategies which arose from a study of direct care staff in a Canadian LTC home that may similarly address these findings. Some of these recommendations include: implementing formal communication strategies to inform all staff following a patient's death, having organizational processes and rituals to acknowledge *all* patient deaths, and recognizing the care providers' experiences and the value of the care they provide to patients at end-of-life.

Based on the findings of this study, specific suggestions for implementing these recommendations in CCC will now be described. When deciding on a communication approach, it is important that this communication and opportunities for team dialogue extend beyond the shift or day when the patient died. The smaller nurse-to-patient ratios and more varied shifts in CCC mean that the care team may be larger than in LTC and nurses may be off for several days in a row. Efforts should be made to ensure staff

members do not feel that they ‘missed’ a patient’s death or the opportunity to discuss it and receive support. Simple strategies to acknowledge the patient who died in the care environment, such as a picture or name on a memorial board (Marcella & Kelley, 2015), can accompany other communication strategies. These practices can create opportunities for staff members to informally reminisce about the patient and acknowledge one another’s experiences. Whichever acknowledgement activity is selected, it should be accompanied by a formal unit process to ensure that it is consistent and maintained in order for nurses to see that all patients are respected.

It is important to reiterate Marcella and Kelley’s (2015) recommendation that unit leadership express to care providers that their care of the patient and family was valued and meaningful. Acknowledgement of nurses’ experiences can be as simple as approaching them individually and asking them how they are doing. Despite the simplicity of these gestures, they can normalize nurses’ experiences and support their individual coping (Maitland et al., 2012). As continuing care settings like CCC develop and implement acknowledgment and support processes for their setting, it should be recognized that multiple forums and activities may be required to meet the diverse needs of nurses and other staff. Nurses with different years of experience may require a variety of types and content of support and education, tailored to where they are in their nursing and life journey. Recognition that casual, part-time, float and male nurses may not feel as connected to the social support network may mean that they need individualized and intentional support and acknowledgement for their experiences. Participants in this study also described that everyone grieves in their own way. This point illuminates that

education and support are needed to foster individual capacity building in skills such as self-care and individual coping strategies (Marcella & Kelley, 2015) for nurses who prefer to grieve privately.

Past research has recommended that support and education activities be peer-led (Anderson et al., 2015; Gerow et al., 2010; Marcella & Kelley, 2015). This recommendation is reinforced by findings of the current study. The participants identified that the most meaningful form of support was the understanding they perceived from their colleagues; from someone who is ‘on the same level.’ Based on the deeper understanding from this study of the uniqueness of novice and experienced nurses’ experiences caring for dying patients, one-on-one mentorship relationships between experienced and confident nurses with novice or uncomfortable nurses should be formally coordinated by unit leadership (Marcella & Kelley, 2015).

Considering these implications, an important first step towards culture change in CCC settings must begin with recognition of CCC as a significant setting in which most patients will remain until they die (Marcella & Kelley, 2015). With openness and acceptance of this, other cultural processes such as communication and acknowledgement rituals may follow naturally.

Implications for Education

It is well accepted that diploma and university programs for nurses should include palliative and EOL care education in order to prepare soon-to-be nurses for this aspect of their practice (RNAO, 2011). This study confirmed the important factor that nurses’ past experiences with death in their lives and practice influence their on-going experiences

(Anderson et al., 2015; Gerow et al., 2010). To facilitate nurses' clinical experiences when patients die in their own practice, it is recommended that nursing education programs provide hands on experience with palliative and EOL care through clinical placements in settings such as hospice palliative care. Having positive early death experiences with supportive mentorship from clinical preceptors and faculty advisors can influence nurses' future experiences in independent practice (Anderson et al., 2015; Gerow et al., 2010).

Other research teams have recommended that professional education and development opportunities about palliative and EOL care be on-going and routinely embedded into staff education (Marcella & Kelley, 2015; Wilson & Kirschbaum, 2011). To tailor this recommendation further for CCC, just-in-time education in the form of small in-services should be used to support nurses in care delivery. The content of this education should focus on the key roles and competencies of nurses identified in this study: protecting the patient, preparing and supporting family members and awareness of policy and procedure. This flexible and timely education is important because nurses in CCC perceive that they care for dying patients infrequently. Nurses may not often be the primary nurse caring for a patient and family when a patient is dying and may therefore require supplementary education. This applied education approach can employ case examples, role playing and practice responses based on the current patient's experience to educate and build nurses' confidence providing EOL care (Wilson & Daley, 1998). In this study it was also learned that most patients in CCC have progressive and predictable

illness trajectories. Therefore, the need for this education can be anticipated and tailored to patients' individual situations and the nurses' learning needs.

Implications for Policy

This study has implications for everyday policies in CCC and potentially other continuing care settings such as LTC, alternative level of care units in acute care and complex care in the community. Respecting the deceased patient and their family's experience was very important to the participants in this study. The quick turnover following patients' deaths led to discomfort for some nurses who felt that the person who died was not respected, forgotten or did not matter. Settings such as CCC could consider creating time buffers of two or three hours that delay the cleaning of patients' rooms and admission of new patients. These person-centered considerations may benefit the deceased person's family members in addition to nurses, who desire to show respect for the person who died. This may facilitate their ability to find resolution in the experience by preparing psychologically and emotionally before a new patient arrives and provide opportunities for individual or group rituals, such as room blessings (Maitland et al., 2012), that are perceived as meaningful to the unit staff.

Several participants from this study described attending or wanting to attend some patients' funeral services to pay their respects. Nurses in LTC also described attending funerals as important to their grieving experience (Gannon & Dowling, 2011). The implications of this finding are that clinical managers should make efforts to support their staff to attend these ceremonies. This will likely require approval of nurses' use of vacation and lieu time, or shift changes on short notice, despite organizational or union

policies. This flexibility is another way that unit leadership can show recognition of nurses' experiences and their desire to acknowledge their patient's deaths. As was reflected upon in the discussion chapter, nurses' desire to attend funerals should be explored by clinical leaders or in future research to identify nurses' motivation for attending such ceremonies. This activity may reflect an attempt to meet the nurses' personal needs as opposed to being a part of therapeutic care for the patient's family. A formal policy of having unit representation at patients' funerals could become a part of care planning for patients who die in CCC.

Finally, some participants in this study and in past research reported that participating in interviews in which they shared their memorable experiences was perceived to be beneficial (Anderson et al, 2015). Reflection is an important part of quality assurance in nurses' practice (CNO, 2015; Fitzpatrick, While & Roberts, 1992), and the interview was an opportunity for nurses to formally reflect upon formative experiences in their practice. Based on the interest and acceptance of reflection by nurses in this research setting, supporting nurses to engage in facilitated reflection among peers or individually may benefit nurses' in finding resolution with individual patient deaths and in their journey of integrating death experiences while supporting them to meet regulatory requirements.

Implications for Research

This study also has implications for the direction of future research into nurses' experiences of patient death in CCC and other continuing care settings. A key finding from this study and Marcella and Kelley's (2015) study was that unit and organizational

culture is critical to understanding nurses' perceptions of support and acknowledgment. This suggests that a focused-ethnographic approach (Knoblauch, 2005; Muecke, 1994) may deepen the understanding of the complex social and cultural factors influencing nurses' practice experiences of death in the setting of CCC. More formally exploring culture of a setting around patients' death might require expanding the sample to include other staff members such as allied health, support staff, PSWs, clinical managers, organizational leaders, CCC patients and their family members. A grounded theory study could further the nursing discipline's understanding of the social process of *how* nurses progress through their journey of experiences with patients' deaths which was introduced in past literature (Anderson et al., 2015; Gerow et al., 2010) and more fully described in the current study.

Mixed-methods studies are needed to evaluate the benefit and perceived acceptability of support and education interventions for nurses and other carer providers in continuing care settings. This would support clinical leaders to make informed decisions about which interventions to implement in their respective organizations and units. Based on the multiple needs of staff including education, emotional debriefing, and case conferencing (Wickson-Griffiths et al., 2015) and nurses' individual ways of coping when patients die, it is recommended that more studies evaluate the benefit and impact of multi-component support and education programs, such as Kaasalainen's and Sussman's multiple case study of a comprehensive palliative approach to LTC (Kaasalainen, Sussman, Rimap, & Vahrmeyer, 2015). It is also important that studies are conducted to bring attention to male nurses' experiences in continuing care settings since it was found

that male nurses may feel excluded from the informal network of collegial support.

Owing to the importance that participants placed on the support of their colleagues, male nurses' experiences of patient death and support needs and preferences should be explored to develop more comprehensive practice recommendations.

This study also has implications for the use of Chirban's (1996) interactive-relational approach to interviewing. The IR approach facilitated the collection of rich critical incidents as recommended by Schluter and colleagues (2008) and this approach bridged the concreteness of CIT with Thorne's interpretive description methodology. I would recommend this method to other novice researchers new to qualitative interviewing, as it provided a practical and flexible framework for conducting qualitative interviews.

Finally, the horizon of CCC and nurses' experiences when patients die will change as a result of Canada's new legislation for medical assistance in dying (MAID). People suffering with progressive and incurable conditions in CCC may seek MAID. This would have impact upon the *types* of deaths that nurses experience in CCC. In addition, this study described how nurses' values about dying and death influence and are influenced by their experiences with patients' deaths. Caring for patients who request or receive MAID and supporting their family members may challenge nurses' personal values and be unique from their prior experiences. This will also have implications for nurses' support and education needs, and future research will be required as MAID becomes part of the landscape of dying in CCC.

Summary of Implications

The findings from this study have important implications for practice application, education, policy and research. Creating a culture that is open about patients' deaths and that normalizes nurses' and care providers' experiences should be a priority for organizational leaders. First recognizing CCC as an important setting where many patients die may positively influence unit processes and policies so that nurses' feel more supported in their experiences. On-going professional development and education for nurses in continuing care settings should focus on areas that nurses have identified as important to their role in EOL care and may need to be tailored to the different needs of novice and more experienced nurses. Unit leaders can build upon and optimize existing informal support networks among nurses by implementing initiatives such as mentorship programs for new nurses caring for dying patients. A fuller understanding of the phenomenon would result from further research in CCC using methods such as grounded theory, focused ethnography and mixed methods evaluation studies, and studies focused on male nurse experiences and support needs in continuing care settings.

Conclusion

This study deepens our understanding of nurses' experiences of patient death in continuing care settings and increases our awareness of how nurses' experiences may be unique in CCC. Learning from critical experiences from nurses' practice makes it clear that their experiences are complex and involve fulfilling different nursing roles, while simultaneously responding to the patient's death as a human. Notable factors influencing nurses' experience were their years of experience and past experiences with death. This

study adds to the understanding of nurses' experiences as a journey in which nurses' attitudes and values towards dying and death change over time, influencing their future practice and lives. Nurses' experiences include acknowledging the person who died and feeling supported which are closely tied to unit and organizational cultures. It is apparent that nurses require preparation and support to manage this aspect of their practice and implications for practice, education and policy must be based on the acknowledgement of CCC as a setting where many patients die. Just-in-time education, peer mentorship and targeted support may facilitate nurses' ability to find resolution in the experience and support their on-going journey towards integration. Further research of multi-component support and education interventions and a deeper understanding of the influence of nursing practice environments on nurses' experience will inform more comprehensive recommendations for practice.

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Appendix A

Glossary of Terms

Advanced Practice Nurse: Nurses with graduate-level education who provide clinical leadership through synthesis of in-depth knowledge of clinical practice, theory, research and education (CNA, 2008).

After death care: Care of the person's body after their death, including washing, dressing and positioning (Horst, 2015).

Comfort Care Rounds (CCR): A facilitated forum that provides palliative and EOL care education to interprofessional and paraprofessional LTC staff while incorporating formal and peer support by acknowledging staff experiences and emotions (Wickson-Griffiths et al., 2015)

Complex Continuing Care: A care setting for patients who no longer require acute care, however whose care needs exceed the capacity of home care or other care settings (CIHI, 2014; Ontario Ministry of Health and Long Term Care, 2010). Patients in this specialized service are medically complex and their conditions require hospital stay, monitoring and management by an onsite physician and active care by other trained staff (OHA, 2006). Other terms for this service include extended care, continuing care or chronic care (CIHI, 2014).

Continuing Care: Secondary health care services where patients receive specialized care (Health Canada, 2012). In this study, continuing care is used to refer to setting where patients are cared for over longer periods of time, such as long term care, complex continuing care and rehabilitation.

Critical incident: Critical incidents are memorable “events, activities or role behaviours, which affect the outcomes of [a] system or process” (Schluter, Seaton & Chaboyer., 2008, p. 108). For this study, a critical incident was defined as any memorable patient death experience which occurred in CCC.

Critical Incident Technique (CIT): A systematic set of procedures which can be used to facilitate an understanding of everyday practical problems (Flanagan, 1954; Janes et al., 2009; Kempainen, 2000).

End-of-life (EOL) care: Care provided to patients that are likely to die within the next 12 months. The main context of the term used in this study care for patients whose death is imminent (expected within a few hours or days). Term may also apply to EOL care for patients with: (a) advanced, progressive, incurable conditions; (b) general frailty and co-

existing conditions; (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; (d) life-threatening acute conditions caused by sudden catastrophic events (General Medical Council, 2010)

Interpretive description (ID): A qualitative research methodology which supports inquiries into health and illness experiences of people from an applied health perspective (Thorne et al., 1997; Thorne et al., 2004; Thorne, 2008).

Gold Standard Framework (GSF): The GSF for Care Homes is a training and education accreditation program which aims to improve care of residents approaching end of life, improve coordination and collaboration among health care providers and improve cost effectiveness of this care by reducing hospitalization (National GSF Centre, 2016)

Interactive-Relational (IR) Approach: An approach to qualitative interviewing that promotes engagement with participants, contributing to a deeper understanding of their experiences (Chirban, 1996; Schluter et al., 2008).

Licensed nurses: Regulated nursing professionals who may be either registered nurses (RN) or registered practical nurses (RPN). In this study, the term licensed nurses is used interchangeable with nurses. Licensed nurses perform four controlled acts under the Regulated Health Professions Act (1991) (CNO, 2014a). Their practice scope and autonomy differ based on the complexity, predictability and potential for negative outcomes relating to a patient's care (CNO, 2014a; HealthForceOntario, 2015) and roles defined by the organization.

Multiple Sclerosis (MS): MS is an autoimmune disease of the central nervous system that attacks myelin, the protective covering of the nerves. MS can cause symptom such as extreme fatigue, lack of coordination, weakness, tingling, impaired sensation, vision problems, bladder problems, cognitive impairment, and mood changes. There is currently no cure (MS Society of Canada, 2016)

Appendix B

Literature Review Search Terms

1.	patient death palliative care end-of-life care terminal care terminally ill patient
AND	
	nurs* health care provider
AND	
	extended care chronic care complex continuing care skilled nursing facility long term care continuing care
1a) AND	1b) AND
staff grief nurses' grief loss professional bereavement psychological stress coping stress grief grieving response experience	support grief support emotional support formal support informal support organizational support bereavement support psychosocial support
AND	
2.	attachment nurse-patient relationship care-provider resident relationships nurse-patient relations
AND	AND
2a) extended care chronic care complex continuing care skilled nursing facility long term care continuing care	2b) Patient death Palliative care end-of-life care terminal care terminally ill patient

Appendix C

Literature Review Articles

Study Methods	Studies and Articles
Phenomenological Philosophy	Anderson et al., 2015* Gannon & Dowling, 2012* Gerow et al., 2010* Hopkinson et al., 2005 Wilson, 2014
Survey Methods	Gibson et al., 2008 O'Hara et al., 1996* Rickerson et al., 2005 Sumaya-Smith, 1995
Literature Review or Concept Analysis	Kehl, 2006 Wilson & Kirschbaum, 2011 Zolnierek, 2014
Theoretical	Papadatou, 2000
Generic Qualitative (description or interpretive)	Copp & Dunn, 1993 Katz et al., 2001 Maitland et al., 2012 Marcella & Kelley, 2015* McGilton & Boscart, 2007 Waldrop & Nyquist, 2011 Wickson-Griffiths et al., 2015 Wilson & Daley, 1998*
Grounded Theory Technique	Munn et al., 2008*
Ethnographic Approach	Costello, 2006

**Studies which were critical to informing the literature review due to their rich descriptions of different aspects of nurses' experiences with patient deaths*

Appendix D

Recruitment Email

Title: Research opportunity for CCC nurses! Let's remember our patients who have passed.

Dear Nurses of CCC,

I am inviting you to participate in a study called **Nurses' Experiences of the Death of Patients in Complex Continuing Care (CCC)**. I am interested in exploring how patient death in CCC influences nurses, both personally and professionally. If you have worked in CCC for 6 months and can recall a memorable patient death experience, then I would love to speak with you!

Participating will involve speaking with me about one or two memorable patient deaths from your practice in CCC. Each interview will take approximately 30 to 60 minutes. A \$10 gift card to Tim Horton's will be offered to you to thank you for your time.

The information collected will be kept strictly confidential and your individual experiences, opinions or comments from the interview(s) will not be shared with hospital or unit management. You can stop the interview at any time and refuse to answer any questions.

I would like to give a voice to CCC nurses regarding this experience, and use it to help inform educational and support resources for nurses.

Please contact me for more information at 416-452-9760 or whitbyca@mcmaster.ca

Thank you for your time and consideration!

Christy Whitby, RN, MScN (student)
McMaster University

Appendix E

Recruitment Poster

4East/West RPNs & RNs!

Let's remember our patients who have passed

Share your experiences by participating in the research study: **Nurses' Experiences of the Death of Patients in CCC.**

What does it involve?

- One-on-one interview
- 30-60 minutes of your time

For more information, please contact:
Christy Whitby
416-452-9760
whitbyca@mcmaster.ca

TIM HORTON'S CERTIFICATES PROVIDED!



Appendix F

Direct Care Nurse Interview Guide

Study Background Information:

This study is being conducted to explore how the death of a patient can influence nurses in complex continuing care (CCC). This is important because the demand for CCC is increasing and it has become a significant place for patient death. It is important that leadership in these areas understand the experience of their staff and know how to properly support them. I appreciate you taking your time to speak with me today.

1. a). Tell me about a memorable death of a patient in CCC that you feel **went well**.
OR b). Tell me about a memorable death of a patient in CCC that you feel **did not go well**.

Revised: Please tell me about a memorable experience you had on the complex medical service, when you cared for a dying patient or a patient who died.

Critical incident probes:

- Describe the patient's dying experience
 - What was the approximate age of the patient?
 - What was the level of acceptance of the team and family towards the patient being near end-of-life?
 - Was there a palliative care plan in place for this patient? If yes, what did it involve?
 - How well were the symptoms of this patient managed?
 - If you were present for the patient's death, please describe the patient's death event
 - Was patient's death expected or unexpected?
 - Who was present for the patient's death?
 - Did the patient seem comfortable?
 - If you were not present, how did you learn about the patient's death?
 - How much time has passed since this patient's death?
2. How did this patient's death make you feel?

Revised: How did you feel during this experience?

Probes:

- How long did these feelings last?
- How did these feelings or emotions change over time?
- Do you still think of this patient or their death? If yes, what do you think about?
- What triggers these thoughts?

3. What about this death or experience made it memorable? Why do you believe that this death or elements of it have stuck with you over this amount of time?

4. What elements of this experience make you feel that this death went well or did not go well, or was good or bad death?

Revised: What elements of this experience make you feel that it was a more positive or more negative experience?

5. What was your relationship like with this patient before they died?

Probes:

- How long did you care for them?
- Did you feel that you had a special connection with this patient? If so, can you tell me more about that?
- What was your relationship like with the patient's family or friends?

6. What did you do to acknowledge this patient's death?

7.

Revised: When this patient was dying or after they died, other than provide comfort care measures or after death care according to policy, what did you do to acknowledge this patient's death?

Probes:

- **Added:** Other nurses have mentioned things such as taking a quiet moment to reflect on the patient or attend a funeral service.
- **Added:** Something you say or a ritual
- Spiritual/religious practices
- Attend funeral or memorial service
- Celebrate their life
- Share stories/memories with colleagues or patient's family

8. How did you personally manage your feelings or cope with this patient's death?

Revised: You mentioned that you felt _____ and/or _____, how did you personally manage your feelings or cope with this patient's death during and after this experience?

9. What kind of support did you receive or seek out while this patient was receiving palliative/end-of-life care or after they died?

Probes:

- Support from colleagues?
- Support from leadership or organizational resources?
- Support from non-nursing friends or family?
- **Added:** [Probes for novice nurse] – As a student nurse or new member to the nursing team, how supported did you feel by your colleagues or the nurses?
- **Added:** I often heard from other nurses about the importance of support from your nursing colleagues, as a newer nurse or a male nurse, what has been your experience?
- **Added:** In this experience, what kind of support or education did you receive from the organization or unit leadership?
 - In what ways would you want to be supported or would it be appropriate for the organization to support you?

10. What supports were most helpful or were the most meaningful for you?

Probes:

- Why do you prefer this type of support over another?
- How could your organization support you better?

11. Having just reflected on the death of your patient, what has this experience meant to you and in your life? How has it influenced...

Revised: Having just reflection on the death of _____ or this experience, what did you learn or take away from this experience?

Probes:

- Your nursing practice
- Your care of other patients who are dying or who have died in CCC
- Your personal relationships
- How you live your life
- How you think about dying and death

Appendix G

Nursing Practice Leadership: Interview Guide

Study Background Information:

This study is being conducted to explore how the death of patients can influence nurses in complex continuing care (CCC). This is important because the demand for CCC is increasing and it is a significant place for patient death. I am speaking with nurses in practice leadership positions to explore this experience from another perspective. I am also interested in exploring how leaders perceive the experiences of direct care nurses in CCC. I appreciate you taking your time to speak with me today.

1. As a nursing practice leader, what role do you play in palliative, end-of-life or after death care in CCC?
2. What does palliative and end-of-life care look like in complex continuing care?
 - Who is involved?
 - What are the nurse-patient ratios?
 - Where does it occur?
 - What policies exist in this setting to guide this care and how do they direct nursing care?
3. What is your perception of the nature of the relationships that develop between patients and the nurses over time in CCC?
4. What are the implications of this relationship for nurses when a patient is dying or after a patient dies?
5. What is your perception of the experience of nurses as they care for patients approaching the end of their lives and after the patient has died?
 - What kind of things about the nurse, patient or care setting influence their experiences?
6. What types of support or education are available to nurses to prepare them for patient death or support them when a patient has died?
 - Example Chaplaincy, counselling services, organizational ceremonies to recognize patients
 - How are these services used?
 - What barriers and facilitators exist to nurses accessing these resources?

7. How are nurses encouraged to enhance their knowledge and skills specific to palliative or end-of-life care within your organization? How does the organization support this?
8. What kinds of things do nurses do in complex medical service after a patient dies to acknowledge the person's death? How is the death of a patient communicated to nursing staff?

Probes:

- Organizational memorial services
 - Attending patient's funeral
 - Individual staff rituals/celebrations
 - Unit-specific rituals/celebrations
9. What is your perception of how CCC nurses respond to and/or cope with the death of patients?
 10. Can you tell me about a memorable experience from your practice in a leadership role, when you were involved in interacting with a patient or their family, or supporting/educating staff when a patient was dying or after they died?

Appendix H

Participant Demographic Questionnaire

Date: _____

Participant ID #: _____

1. Age

- 20-30 years
- 31 - 40 years
- 41-50 years
- More than 50 years

2. Gender

- Female
- Male
- Other

3. Education:

- College diploma
- University degree
- Other: _____

4. Job title:

- Registered Practical Nurse
- Registered Nurse
- Advanced Practice Nurse
- Other: _____

5. Employment status:

- Full-time
- Part-time
- Casual
- Other: _____

6. Years of nursing experience:

- 1-5 years
- 6-10 years
- 11-15 years
- 16-20 years
- More than 20 years

7. Years of experience in CCC?

- 1-5 years
- 6-10 years
- 11-15 years
- 16-20 years
- More than 20 years

8. Number of patient death experienced in last 6 months?

- 0
- Less than 3
- 4-6
- More than 6

9. Have you had additional palliative care or end-of-life care training/courses since registering as a nurse or practical nurse?

Please describe:

Title of course (if applicable): _____

Organization where completed: _____

Year completed: _____

Approximate # of hours: _____

Other information if required:

Appendix I Early Coding Scheme

Main Idea	Main Code (with Sub-codes)	Main code definition
Experience of patient death	Resolution <ul style="list-style-type: none"> • Acceptance • Filled with love • No resolution [conflict, distress] • Retrospective, over course of experience, anticipatory 	Despite patient suffering, team/family/internal conflict, negative emotions – nurses/family members achieve acceptance and understanding of the patient's death
	Death as a relief <ul style="list-style-type: none"> • No more suffering • Death as good for the patient 	Patient's death is understood as better than patient going on in current condition with little quality of life
	Family Care <ul style="list-style-type: none"> • Facilitating family experience • Preparing and supporting families • Worrying about the family 	A significant portion of the experience involves working with and meeting family needs leading up to and after patient's death
	Emotional Experience <ul style="list-style-type: none"> • human experience • anger, sadness, grief, unsure how to feel, surprised 	The dying and death of a patient can be emotional for nurses during experience and emotions may re-surface during interviews when nurses describe critical incident
	Practical aspects surrounding experience <ul style="list-style-type: none"> • Following policy and procedure • 'left brain' part of experience • providing after death care 	Nurse discusses the practical aspect of the experience when providing after-death care
	Loss <ul style="list-style-type: none"> • grief 	Perceiving the patient's death as a personal loss or experiencing grief
Managing/ Reconciling Experiences	Nursing Support <ul style="list-style-type: none"> • only nurses understand • good team support • on the go support/looking out for each other • behind closed doors • mentorship/learning from more experienced nurses • keeping each other informed • not always inclusive 	Informal support from nursing colleagues who can relate to experience and also knew patient is important to nurses' experiences
	No Formal Support <ul style="list-style-type: none"> • not openly discussed/code of silence • no time, too busy • -desired formal support [acknowledgment, sensitivity, communication 	Perceived absence of organized/consistent support within organization/service to prepare nurses for patient death experiences including support/education as patient dies or after death

	<p>Acknowledging death and Individual Coping</p> <ul style="list-style-type: none"> • avoiding • maintaining hope • rationalization [r/t quality over quantity, no suffering..] • remembering the positive/ reframing • compartmentalizing/delayed • knowing you did your best/all you could • attending formal services • reminiscing with other nurses • personal expressions [prayer, crying, reflecting, talking to body] 	<p>Nurse's personal and individual ways of coping/managing patient death experiences. In general, described as a very personal and private journey</p>
	<p>Learning from experience [integrating]</p> <ul style="list-style-type: none"> • in personal life [<i>talking to own family about own EOL wishes, forming attitudes about death</i>] • for future practice [<i>learning to support families, advocating, try not to get attached, prioritizing care of dying patients, being balanced/looking for quality</i>] 	<p>Ways in which nurses incorporate critical experiences of death into future practice or their personal values and beliefs surrounding death</p>
	<p>Nurse-patient-family relationships</p> <ul style="list-style-type: none"> • 'not favourite-favourite patient' • patient feels like family • Family as part of care team • long-term relationships/knowing the patient • special connection between pt/family and nurse 	<p>Interactions and dynamics between patient /family and nurse that influenced experience of patient death or nurse's response after patient death</p>
<p>Factors influencing experience</p>	<p>Nurse Factors</p> <ul style="list-style-type: none"> • Nurse's culture & values • Nurse's preparation and expectations surrounding death • Comfort with palliative/EOLC • Past death experiences • Expectations about death • perception of death quality [good/bad] 	<p>Qualities or nurse-specific traits which influence nurse's experience</p>
	<p>Patient/Family Factors</p> <ul style="list-style-type: none"> • disease process • age • patient/family roles • no family or patient dies alone 	<p>Qualities or patient/family-specific traits which influence nurse's experience</p>

	Context Factors <ul style="list-style-type: none"> • bed turnaround/demand • busy environment/heavy workload • general patient population [chronic, progressive illness, long stay] • No respect for death (here or No formal Support?) 	Characteristics and processes of the unit, organization or complex care service which influence nurse's experience
Early Themes	<hr/> Overarching: Finding Resolution & Internalizing/integrating Experience <ul style="list-style-type: none"> • Acknowledging, being sensitive and respectful • Nurses want this from families, each other and leadership, policies/procedures • Family theme – nurses experiences interwoven with the family/patient unit, fine line between nurses and family • Family-like relationships between nurses/family/patient • Family members as part of the care team • Nurse's experience closely related to family's • Supporting each other • Complex care context and death • Individual and private experience • Expectation/preparation – plays a significant role in experience • Quality over quantity [tied to context, disease processes...] • Respect for life [added Jan29] – both a desire by nurses for unit processes to show this and also something they learn from the experience <hr/>	

Appendix J

Revised Coding Scheme

Main Idea	Main Code (with Sub-codes)	Main code definition and analysis notes
Experience of patient death	Patient Care <ul style="list-style-type: none"> • Keeping patient comfortable • After death care • Policy and Procedure 	Practical aspect of providing nursing care during memorable experience such as providing PRN medications or washing deceased person's body. <i>*Sub-code of keeping patient comfortable evolved to sub-theme of protecting the patient. Together with preparing and support families and policy and procedure formed subthemes of nurses' experience and key roles when patients die</i>
	Tied to family experience <ul style="list-style-type: none"> • Preparing and supporting family members • Worrying about families • Respecting family wishes 	Participants' description of their experience centers on the family or different aspects of supporting them during their experience <i>*Together with patient care codes informed main theme of experiencing patients' death as a nurse and the key nursing roles</i>
	How it feels <ul style="list-style-type: none"> • Death as a relief • Loss and Grief • Individual and private • Rewarding • Unsure how to feel • Feeling uncomfortable • Delayed emotional experience • Other emotions [Anger, sadness, love, surprise] 	References made by participants to how they felt and emotions experienced during memorable experience/incident. <i>*Prominent sub-codes from this section (e.g. relief, comfort) informed sub-themes of nurses' personal experience when caring for dying patients in CCC.</i>
	Resolution <ul style="list-style-type: none"> • Maybe it was for the best [finding peace in patient's death] • Anticipatory • Retrospective • No resolution [conflict, distress, regret] 	Participant reflects on overall sense of how the experience ended considering the patient's, family's, and their own experience towards a feeling of closure and acceptance of the experience. This understanding may have been achieved before patients' death or after some time following their death <i>*Became an important and stand-alone theme to understanding the overall experience of each individual death</i>

Factors influencing Nurses' Experiences	Nurse-Patient-Family Relationships <ul style="list-style-type: none"> • Knowing the patient/long term relationship • Loving the patient • Special connection with patient • Relationship boundaries (feeling like patient's family member, family part of care team) 	Descriptions of the nature of relationship between nurse and patient/family in critical incident and how they influenced the nurse's experience
	Patient-Family Factors <ul style="list-style-type: none"> • Goals of care • Dying alone/No family • Disease process/symptom management • Patient/family characteristics [e.g. age, roles..] • Filled with love 	Characteristics of the patient, their disease, the family dynamic or roles which contributed to nurses' perception of their experience (e.g. the patient had suffered for many years, the patient was young)
	Nurse-related Factors <ul style="list-style-type: none"> • Culture and values • Expectations and preparation • Comfort with end-of-life care • Past death experiences • Perception of death quality [good death/bad death] • Sense of control 	Individual attributes of the nurse which contributed to their perception and experience of a memorable patient death (e.g. expected the patient to live longer, first time caring for a dying patient)
*Key factors were embedded in the main themes as they were important for understanding each theme and nurses' experience in CCC	Contextual Factors <ul style="list-style-type: none"> • Bed turnaround • Heavy and busy • Patient population/types of death • Organizational/unit culture related to dying and death 	Elements of the organization, unit or care setting of CCC which were described in relation to the nurse's experience or perception of the experience as positive or negative <i>*Became very important to understanding what was unique about nurses' experiences in CCC as compared to other care settings.</i>
	Perceptions of Support	There's None <ul style="list-style-type: none"> • No time/too busy • Not openly talked about • Not knowing what is available
Desired Support <ul style="list-style-type: none"> • Acknowledgement of nurse's experience • Respecting patient • Sensitivity for family and nurse experience • Communicating to nurses when patients die • Education/preparation • Opportunity for team dialogue 		Participant describes type of support that would have been helpful, meaningful or would have improved their experience.

	Nurses' Supporting One Another <ul style="list-style-type: none"> • Only nurses understand • Good team support (looking out for each other) • On-the-go support • Mentorship • Reminiscing together 	Participant speaks about importance of support from other nurses or descriptions of why nurse collegial support is helpful
	Family feedback <ul style="list-style-type: none"> • Knowing they will be ok • Family is thankful for care 	Nurse describes how knowing that family will be ok in their grief and that they are happy about care provided to patient helps their experience
Nurse' acknowledging and coping with patient's death	Attending services	Participants talks about attending, wanting or not wanting to attend funeral or memorial service for patient
	Reflecting and Remembering	Nurse describes reflecting about the patient and positive interactions they shared over the time of their stay in CCC to honour them after their death.
	Personal expressions (crying, talking to the body, praying)	Individual ways that nurses expressed their emotions or acknowledged patient in incident
	Coping with Death <ul style="list-style-type: none"> • Maintaining hope • Reframing death [e.g quality of life over quantity, looking for positive] • Compartmentalizing • Avoiding • Doing your best • Soul searching 	Personal strategies employed by participants to manage or cope with patients death in the moment or over time
	Forming attitudes about death	When participant describes that memorable experience contributed to and shaped their values and beliefs surrounding death in their lives
Learning from experience <i>*Later contributed to key theme of Integrating Professional and Personal Experiences</i>	Influencing future nursing practice	When participant speaks to how they may act or feel differently in future experiences as a nurse caring for dying patients
	Preparing for future deaths	Participant anticipates future deaths in their practice or family and how this memorable experience helps them prepare (e.g. thinking and talking about their wishes to spouses and family members)
	Memorable Deaths <ul style="list-style-type: none"> • When not primary nurse 	Circumstances of a patient's dying process or death and the nurses' experience which led to the participant sharing the story as a memorable practice experience.
Other codes	Good quotes	Rich quotes which capture main ideas to save and draw on in presenting findings

IR Approach examples	To facilitate reflection of use of Chirban's IRA
Important but don't know where to put	This section was helpful to evolve analysis and ensure important concepts were not missed in analysis.

**Notes about how coding and theming evolved during analysis*

Appendix K

Analysis Examples of Coding and Returning to Raw Data

Transcript Excerpt	Early Codes Applied
<p>I: what are they doing differently on the palliative care unit that might be helpful here?</p> <p>P: A lot of it is the way that the patients are treated...um, I just find, there's staff there that, our staff just don't have that um, I don't know what the word is...the nurturing, the caring for the patient. I don't know, they just, they're just like any other, they're more rushed, rush, rush, get their work done. I hate seeing that, I hate seeing it..you know, treat that person the way, like they were your own...and it should be that way with any patient whether they're dying or not...you know what I mean?</p> <p>In a sense, you have to be a certain way I feel...and our floor is very hard, it's very heavy, you have to get things done and its, we find the, the ones who've been there a long time, we like to give our patients a certain level of care where uh newer staff or staff from other hospitals, they don't have that yet</p>	<ul style="list-style-type: none"> • Practical experience • Patient Care • Context factors • Org and unit culture surrounding dying and death • busy environment/heavy workload • patient population and types of death • comfort/experience with EOLC • nurse's culture and values • past death experiences
Reflections from Returning to the Raw Data	
<p>Different nursing approach to patients at end-of-life, nurturing the patients, especially those who are dying.</p> <p><i>Do all CCC nurses have resources, capacity, knowledge, support, comfort to provide this care?</i></p> <p>Discomfort with task-focused care of patients in CCC 'I hate seeing it.' Can feel discomfort and upset of participant when she sees this type of care. 'Treat them like your own.'</p> <p><i>Nurses develop a sense of duty to their patients, to care and ensure they receive quality care and are protected from harm. Makes me think of consistent use of 'our patients,' sense of ownership</i></p> <p>There is a difference in care provision between experienced and inexperienced staff which leads to conflict among staff</p> <p>Taking pride in the care provided</p>	

Appendix L

Consent Form

**INTERVIEW LETTER OF INFORMATION AND CONSENT
(Version #2 November 09, 2015)**

Nurses' Experiences of the Death of Patients in Complex Continuing Care: An Interpretive Description Study

Investigators:

Local Principal Investigator:

Dr. Sharon Kaasalainen
Department of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140, ext 22291
E-mail: kaasal@mcmaster.ca

Student Investigator:

Christy Whitby, RN, BScN
Department of Nursing
McMaster University
Hamilton, ON, Canada
Phone: 416 452 9760
E-mail: whitbyca@mcmaster.ca



Introduction

You are invited to participate in a graduate student research project conducted under the supervision of Dr. Sharon Kaasalainen. This form will give you information to help you decide if you would like to participate in this study. This information will be discussed with you in person. Once you understand what is involved and are comfortable participating, you will be asked to sign this form.

What are we trying to discover?

Complex continuing care (CCC) is a setting in which patients may spend years of their lives and where they may die. Research shows that caring for patients at the end of their lives and after their death is difficult for nurses. In settings where nurses and patients know each other for a long time, it may be more difficult for nurses. Very little research helps us to understand this experience, especially in CCC.

The purpose of this study is to learn about nurses' experiences with the death of patients in the CCC setting. This will include exploring what nurses want and need in the form of support during this experience.

What will happen during the study?

If you volunteer to participate, you will be asked to take part in one individual interview. The interview will likely be 30 to 60 minutes long. You will be asked questions to share stories from your practice about the death of a patient in CCC, and your perceptions of support resources and factors which may influence this experience. You will also be asked to complete a short survey, with questions about things such as your age, role and years of experience. You may be asked to participate in a follow up interview at a later time.

With your permission, the interview will be recorded. The recording will be typed up and then deleted after the interview. Interviews will be conducted with registered nurses, registered

practical nurses and nursing practice leaders. All of this information will be looked at together in order to explore nurses' experiences of patient death in CCC.

You will receive a copy of this consent form, signed by you and the student investigator.

Are there any risks to doing this study?

It is unlikely that you will experience harm or discomfort during the study. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You may stop to take a break at any time during the interview and you may stop taking part in the study at any time.

Are there any benefits to doing this study?

It is unlikely that this research will directly benefit you. However, you may find it therapeutic to discuss your past experiences of when a patient has died. The results of this study may lead to improved education and the development of acceptable supports for nurses in this setting.

Payment or Reimbursement

To thank you for your time a \$10 gift card to Tim Horton's will be given to you at the end of the interview.

Confidentiality

You are participating in this study confidentially. Your name or any information that would identify you will not be used in the study results or publications. In addition, your individual experiences, opinions or comments from the interview(s) will not be shared with hospital or unit management. However, we are often identifiable through the stories we tell. Every effort will be made to limit the details of your patient stories when reporting this study. The focus of this research is to describe the shared experiences of all participants and therefore it is unlikely that you or your personal experience will be identified through the report.

Confidentiality will be maintained by using a code to identify your transcript and quotes. I will store all identifying information in a locked cabinet or encrypted electronic document. Only the student investigator and study supervisor will have access to your information. This information will be immediately destroyed after the study. An archive of data from this study will be kept for 5 years. None of this information will have any identifying information about you. This may be used for further research.

b) Legally Required Disclosure

I will protect your privacy as outlined above. Your information will not be shared with anyone except with your consent or if required by law.

What if I change my mind about being in the study?

If you decide to participate, you may stop at any time. If you want to withdraw, there will be no consequences to you. The information that was collected from you up to the point where you withdraw will be kept unless you ask that it be removed. In order to withdraw from the study, please inform Christy Whitby or Dr. Sharon Kaasalainen through telephone or email message.

If you decide to withdraw from the study more than two weeks from your interview, your individual stories and quotations will be removed from the study findings. However after this time period, it may not be possible to remove all aspects of your experience from the study analysis.

You can still be in the study even if you do not answer all of the questions. Your decision to be involved with the study will not affect your employment or personal life.

How do I find out what was learned in this study?

I expect to complete this study by August 2016. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study, please contact Christy Whitby:

By email: whitbyca@mcmaster.ca

By phone: 416-452-9760

You may also contact the study's supervisor, Dr. Sharon Kaasalainen:

By email: kaasal@mcmaster.ca

By phone: (905) 525-9140, ext 22291

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Christy Whitby and Dr. Sharon Kaasalainen of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a signed copy of this form. I agree to participate in the study.

I would like to receive a summary of the study's results. Yes No

If yes, where would you like the results sent:

Email: _____

Mailing address: _____

Name of Participant (Printed) Signature Date

Consent form explained in person by:

Name and Role (Printed) Signature Date

Table 1

Literature Review Overview

Main Section Titles	Sub-section Titles
Experiencing and Acknowledging Patients' Deaths	Reprioritizing Care
	Remembering and Reminiscing
	Ceremonies and Rituals
	Nurses' Emotional Experience When Patients Die
Factors Influencing Nurses' Patient Death Experiences	Organizational and Care Setting Attributes
	Nurse-Related Factors
	Patient Characteristics
	The Nurse-Patient Relationship
Nurses' Perceptions of Support and Individual Coping Strategies	Informal Support
	Formal Support
	Support Interventions
	Coping with Cognitive Strategies
	Coping With Avoidance and Distancing
	Other Coping Strategies

Table 2

Participant Characteristics

Characteristic	Total (N=8)	
	<i>n</i>	%
Age		
20-30	1	12.5
31-40	2	25
41-50	3	37.5
50+	2	25
Sex		
Male	2	25
Female	6	75
Nursing Designation		
RPN ^a	4	50
RN ^b	2	25
Nursing Leader	2	25
Years of Experience		
Nursing		
1 to 5	2	25
6 to 10	3	37.5
11 to 15	0	0
16 to 20	1	12.5
20+	2	25
In CCC		
1 to 5	3	37.5
6 to 10	3	37.5
11 to 15	0	0
16 to 20	0	0
20+	2	25

Note. ^aRegistered Practical Nurse, ^bRegistered Nurse

Table 3

Major Themes and Sub-themes

Major Themes	Sub-themes
Professionally Experiencing Patients' Deaths: 'Engaging your left brain'	Protecting the Patient: 'So much love, so much supervision' Preparing and Supporting Families: 'Shifting my focus to the family' Following Policy and Procedure: 'We have to talk about practicalities'
Personally Experiencing Patients' Deaths: 'I'm a human being too'	Being Comfortable with Death: 'I'm just not at that point yet' Feeling Relieved: 'Maybe it was for the best' Emotionally Responding to Patients' Deaths: 'I was shattered'
Seeking Resolution in the Experience: 'It was a good resolution'	Conflict and No Resolution
Integrating Professional and Personal Experiences: 'Applying what you learn in your nursing life into your personal life and vice versa'	
Supporting One Another in a Culture of Acknowledging Patients' Deaths and Nurses' Experiences: 'They expect us just to take it, the nursing profession is like that.'	Communicating About Death: 'It's this unspoken kind of thing' Respecting Death and Acknowledging Each Other's Experiences Feeling Understood: 'They understand me better than anybody else'

Table 4

Memorable Patient Death Incidents

Incident Type	<i>N</i> =13
Central ^a	
Positive	4
Negative	6
Complementary ^b	
Positive	2
Negative	1

Note. ^aCentral incidents were explored in great detail during interviews. ^bComplementary incidents were other memorable incidents shared by participants to compare and illustrate aspects of their experiences in CCC.